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Designing Free-living Quantitative Reports for Parkinson's

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For everyone that deals with this disease.

Resumo

A doença de Parkinson (DP) é um distúrbio neurodegenerativo frequente e progressivo, afetando cerca de 1 % da população mundial. O envelhecimento da população poderá aumentar o número de pessoas que vivem com esta doença nos próximos anos. A DP é caracterizada por tremores, rigidez do tronco e membros. Estes sintomas manifestam-se pela redução dos níveis de dopamina, devido à morte das células cerebrais que a produzem, que ocorre apenas se mais de setenta ou oitenta por cento dessas células morrerem [12] [24] [10] [19].

Embora cada paciente tenha os seus próprios sintomas, esta doença tem, geralmente, como episódio inicial um leve tremor na mão, braço ou perna. A progressão da doença pode provocar instabilidade postural, criando dificuldades nas tarefas de sentar, andar (os passos tendem a ficar mais lentos, arrastados e o normal movimento pendular dos braços não ocorre) e estar de pé. Uma das características da DP é ser altamente variável. Os sintomas, juntamente com o grau de incapacidade, tendem a variar bastante ao longo do dia [24] [19].

Apesar de não existir uma cura, existem algumas intervenções farmacológicas para melhorar a qualidade de vida do paciente, contudo tem de ser aplicadas de acordo com o estado da doença em que o paciente se encontra. Parte dos medicamentos estimula a libertação de dopamina, caso existam células produtoras, caso contrário, é administrada levodopa, que é posteriormente convertida em dopamina [12]. Desafios para a prática clínica incluem a compreensão da progressão da doença, a resposta a intervenções farmacológicas e não farmacológicas, as flutuações diárias e suas possíveis explicações. No entanto, a quantidade de informação disponível para um clínico perceber estas alterações é escassa. Por exemplo, as avaliações são feitas durante consultas clínicas que são espaçadas no tempo e provavelmente as flutuações que ocorrem ao longo do dia não irão ficar registadas [16].

Em ambiente clínico, existem diversos testes que são realizados pelos pacientes: controle postural, locomoção, resistência, sit-to-stand-to-sit e TUG (Time up and go), que ajudam os clínicos a obter dados objectivos sobre o estado clínico dos pacientes. Estudos recentes também mostram que os acelerómetros podem ser usados para obter estes dados. Na clínica existem diversas formas de avaliar os pacientes. Embora as flutuações fora deste ambiente sejam perdidas, pois é em que provavelmente acontecem [11] [7] [4].

Para perceber o que ocorre com os pacientes fora de um ambiente controlado, os clínicos fazem perguntas aos pacientes, contudo é provável que exista menos rigor do que o necessário, pois nem sempre é fácil para os pacientes se recordarem do que aconteceu [15]. Assim, o uso de diários para ajudar os pacientes a resumir o seu dia e fornecer informações úteis aos clínicos é uma alternativa. Diários em papel preenchidos ao longo do dia por pacientes fora da consulta podem ajudar a recolher mais dados em ambiente não controlado. No entanto, existe um problema de "compliance" no uso de diários. Um teste mostrou que diários em papel podem ser não corresponder ao que realmente ocorre na maioria das vezes, pois não são preenchidos no tempo em que deveriam, o que poderá levar a possíveis omissões de eventos. Os diários eletrónicos (DE) podem ajudar a minimizar este problema, aplicando medidas de controlo que garantam a resposta dos pacientes no momento certo ou que registem quando tal não ocorre. No entanto, DE também tem problemas relacionados com o possível esquecimento de preencher o diário, apesar de existirem formas de alertar as pessoas para preenchê-lo. Podem por exemplo não estar perto para detetar os alarmes [15].
Mais recentemente, estudos mostram que as métricas obtidas apenas em laboratório também podem ser usadas em ambiente não controlado com a ajuda de sensores inerciais. Como tal, exista agora forma de complementar os dados subjetivos obtidos pelos diários dos pacientes, utilizando os dados objetivos (energia, sono, atividade física) recolhidos com a ajuda de sensores[6] [5]. Durante a avaliação de um paciente, o clínico tem de realizar múltiplas tarefas, incluindo a recolha de dados dos testes em laboratório e perceber o que ocorreu com o paciente fora do ambiente da avaliação, fazendo perguntas aos pacientes. Os clínicos têm tempo limitado para cada paciente, portanto, introduzir uma nova tarefa pode ser um desafio [16]. No entanto, a consulta orientada aos dados pode ajudar a obter uma visão geral mais objetiva. Com o auxílio dos dados objetivos os clínicos dispõem de mais ferramentas para entender melhor as necessidades dos pacientes [16]. Ainda existem algumas dificuldades em como introduzir as novas ferramentas sem comprometer a forma como a relação entre pacientes e clínicos ocorre. [20]. Esta tese de mestrado foi desenvolvida no LASIGE e faz parte de um projeto que pretende dar mais dados que completem a informação que os clínicos dispões sobre os pacientes. O projeto é composto por três partes, cada uma independente entre si e desenvolvida por diferentes membros da equipa, tendo, contudo, partes em comum. Isso permitiu realizar, em conjunto, entrevistas e grupos de foco sempre que assim se justificou, dando mais contexto sobre todo o projeto e cada parte em específico durante as entrevistas.

O principal objetivo do projeto é criar uma plataforma que ajude os clínicos e os pacientes. Esta plataforma segue uma abordagem baseada em dados para fornecer uma maneira mais fácil, rápida e engenhosa de obter mais dados sobre os pacientes. Esta tese foca-se apenas em ambiente não controlado, tendo como objetivo perceber o que acontece no dia a dia dos pacientes. Para fornecer dados das atividades diárias de atividade

física e análise do sono, é necessário recolher, processar e analisar dados. No entanto, o principal desafio aqui não é como os dados irão ser obtidos, mas sim como devem ser visualizados pelos clínicos para que realmente possam fazer a diferença e ter um impacto sobre como os clínicos interagem com os pacientes. É importante considerar a perspetiva dos clínicos de como os dados devem ser apresentados, mas também o ponto de vista do paciente para obter uma visão mais abrangente de como a plataforma deve ser construída. Os pacientes são o centro da pesquisa, o principal objetivo aqui é tentar melhorar a sua qualidade de vida, ajudando os clínicos a tomar decisões mais informadas e serem capazes de fornecer uma explicação mais compreensível sobre o que ocorre fora do contexto clínico. Existem três sub-objetivos: caracterizar as práticas de avaliação atuais e as suas limitações, pesquisar o estado de arte do sobre o uso de sensores inerciais e desenhar e avaliar uma plataforma utilizável baseada em dados.

O primeiro objetivo pretender dar uma visão geral das práticas atuais da avaliação clínica e as suas limitações, além de mostrar as oportunidades da introdução de uma abordagem baseada em dados no processo.

O segundo objetivo leva a um resumo do que já está a ser feito em termos de pesquisa relacionada com o uso de sensores inerciais. Isso permite entender o que foi validado clinicamente e as limitações que existem e que podem levar a novas oportunidades de pesquisa.

A consulta baseada em dados é um processo que pode levar a uma melhor compreensão dos pacientes por parte dos clínicos. No entanto, não existe uma abordagem que funcione em todos os ambientes possíveis. Na minha pesquisa eu tento perceber se esta metodologia pode ser utilizada e caso seja possível qual será a melhor abordagem para a aplicar.

Com esta plataforma, espero que a qualidade de vida dos pacientes melhore, criando para os clínicos uma nova plataforma que pode proporcionar uma maneira mais fácil de saber qual o estado do paciente fora de ambientes controlados e promover a relação entre pacientes e clínicos.

O DataPark é uma aplicação web capaz de gerar relatórios contendo dados visuais e textuais com base em dados de acelerometria. Os dados ”raw”são processados e analisados pelo nosso sistema com o auxílio de algoritmos. Os dados obtidos são de: energia gasta, atividade física e sono. Para validar a nossa abordagem foram realizados dois estudos. O primeiro teve como objetivo perceber se esta metodologia pode ser aplicada. O segundo consistiu num uso prolongado da plataforma para perceber quais os benefícios e limitações da mesma. Ambos os estudos permitiram concluir que o DataPark pode ser útil para os clínicos, sendo ainda necessário realizar estudos com um maior grau de profundidade para adequar as ferramentas as necessidades dos clínicos.

Palavras-chave: Doença de Parkinson; Tecnologia ; Acelerómetro; Avaliação Objectiva, Usabilidade

Abstract

Parkinson's disease (PD) is a frequent and progressive neurodegenerative disorder, affecting about 1% of the world population. PD is characterized by tremors, rigidity of the trunk and limbs and low movements. With the progression of the disease, the postural instability and the difficulty in walking can be very disabling, making daily tasks more difficult.

Challenges for clinical practice include understanding the progression of the disease, the response to pharmacological and non-pharmacological interventions, and the fluctuations the patient goes through alongside their explanations. However, the amount of information available for a clinician to understand these phenomena is scarce.

This thesis proposes a data-driven approach to improve the amount of information that clinicians have about their patients. The focus is collecting objective data from free-living environment and show it in an proper way for enriching the knowledge of clinicians about their patients. This is part of a larger platform which holds data retrieved in laboratory context and subjective data in free-living.

DataPark allows to generate personalized reports build by clinicians that can adjust according to the needs of each patient. The primary areas of analysis include physical activity and sleep. There is an ongoing collaboration with CNS (Campus Neurológico Sénior) which grants access to patients' data. A preliminary study was performed to understand what are the relevant points of analysis that clinicians want to have.

To validate the use and how DataPark influence the actual process a final study in a real environment was performed where participants could use the platform without any interventions from the research team.

Keywords: Parkinson's disease; Free-living; wearable technology; Data-driven; Accelerometer.

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Chapter 1

Introduction

Parkinson's disease (PD) is a frequent and progressive neurodegenerative disorder, affecting about 1% of the world population. The ageing of the population will increase the number of people living with that disease in the following years. PD is characterized by tremors, rigidity of the trunk and limbs and low movements. It manifests itself by the reduction of dopamine levels, due to the death of the brain cells that produce it, that occurs only if more than seventy or eighty percent of them die [12] [24] [10] [19].

Although each patient presents his own symptoms, the first manifestation of Parkinson disease is a slight tremor on the hand, arm, or leg. With the progression of the disease, the postural instability can be very disabling, creating difficulties in the tasks of standing, sitting, and walking (steps tend to become slower, dragged and without the normal pendular movement of the arms). One of the characteristics of PD is that the disease progression is highly variable and the symptoms, alongside the degree of disability, are likely to fluctuate over the duration of a day [24] [19].

Despite the nonexistence of a cure, there are pharmacological interventions that improve the quality of the patient's life, which should be applied according to the stage of disease in which the patient is. Part of the medications stimulate the liberation of dopamine, if there are producing cells, otherwise levodopa is administered, that is later converted to dopamine at the brain level. [12].

1.1 Motivation

Challenges for clinical practice include understanding the progression of the disease, the response to pharmacological and nonpharmacological interventions, and the fluctuations the patient goes through alongside their explanations. However, the amount of information available for a clinician to understand these phenomena is scarce. For example, assessments are made during clinical appointments which are spaced in time and are likely to miss fluctuations that happen throughout the day [16].

In clinical environment there are several tests that can be performed by the patients:

postural control, locomotion, endurance, repeated sit-to-stand-to-sit and TUG (Time up and go), which help clinicians to obtain measures to better understand the patients' clinical status. Recent studies also show that accelerometer devices can be used to obtain the same data. In clinical evaluation there are diverse ways of getting patients' data. Although, free-living fluctuations are lost, and home is the place where they probably happen [11] [7] [4].

One way for clinicians to understand what happened with the patients in a free-living environment is by asking them questions, but it can be less precise than needed because recall is unreliable [15]. So, the use of diaries to help patients resume their day and provide useful information to the clinicians is an alternative. Paper diaries completed throughout the day by patients outside the appointment can help to collect more free-living data. There is a compliance issue when using diaries. As a test revealed paper diary cards have omissions most of the time, because they are not filled at the required time, so people try to remember what happened in that period of time. Electronic diaries (ER) try to solve that problem by applying control measures that ensure the response of the patients at the right time or register when they not. However, ER also has problems related to the possible forgetting to fill the diary, even having ways to alert people to fill it, but they may not be near to detect the alarms [15].

More recently, studies show that metrics obtained only in the laboratory can be also collected in a free-living environment with the help of inertial sensors. Gait, energy spent, physical activity and sleep analysis are the ones most studies exploit, so now there is a way of complement the subjective data collected from patients' diaries, by using this objective data obtained by accelerometry [6] [5]. Clinicians have to do a lot of task during patients' evaluation, including collecting data from lab tests and try to understand what happen with the patient outside the control environment by asking patients. Clinicians have limited time for each patient so introducing a new task can be challenging [16]. However, data-driven consultation can help in getting a more precise overview based on objective data for clinicians to have more tools to better understand patients' needs [16]. There are still difficulties in how to introduce the new tools without jeopardize the current process [20].

1.2 Context

This master thesis was developed at LASIGE and is part of a major project about providing more and better data to both clinicians and patient. The project is composed of three parts, each one independent of each other and developed by different members, but with common parts. This allows to perform interviews and focus group together whenever justifiable, give more context about the whole project and the specifics parts to the clinicians, by asking all the information at the same time.

The objective analysis has a common part that consists on the usage of an inertial sensor by the patients. In a laboratory context, clinicians use sensors to obtain objective data from patients. For improving the process of evaluation an android app was developed to help with the already performed tests and allowing new ones. After the battery of test is finished a report with the data of the app combined with the sensors' data offers both clinicians and patients an overview of evaluation. In a free-living environment, clinicians only know what patients and their relatives tell them; now with the data from the sensor, they have other ways of obtaining information in an uncontrolled environment. Clinicians can, at any time, have access to a personalized report with the data analyzed. They are now able to explore, filter and personalize each report for each patient.

The subjective analysis consists of clinicians asking questions to patients for them to fill forms at home to provide information about their health state. Currently, this is performed with paper. In the project, automatic telephone calls will be performed at scheduled time (supported by the Interactive Voice Response). The laboratory in objective analysis and the subjective part is out of the scope of this thesis, so it will not be mentioned in detail more than already have been. They can appear in certain parts to explain common concepts or in some of the studies. From this point forward DataPark (or we) will refer to the whole work performed by the team and Free-Living (or I) means the main work of this thesis.

1.3 Research Goals

The main goal of the project is to create a platform that helps both clinicians and patients. This platform will follow a data-driven approach to provide an easiest, fastest and resourceful way of obtaining more data from patients. These thesis as the focus on free-living environments and how it is possible to better understand what happen outside a controlled environment. To be able to provide data from physical activity, sleep and daily activities it is needed to collect, process and analyze data. However, the main challenge here is not how the data will be obtained, but how it should be present to really make the difference and have an impact on how clinicians interact with patients. It is important to consider the clinicians' perspective of how data should be presented, but the patient point of view is also fundamental to get a more embracing view of how the platform should be build. Patients are the center of the research, the main purpose here is to try to improve their quality of life, by helping the clinician on making a more informed decision and being able to give a more understandable explanation of the measures being performed. There are three sub-goals: Characterize the current assessment practices and their limitations, survey the state of art of monitoring with inertial sensors and design and evaluate a usable data-driven platform.

First goal gives an overview of the current assessment practices and their limitations and shows the opportunities for a data-driven approach to be introduced in the process.

Second goal leads to a summary review of what is been done related to research with inertial sensors. This allows to understand what has been clinical validated and the limitation that can lead to new opportunities of research.

Data-driven consultation is a process that can lead to better understanding of patients by clinicians. However, there is not an approach that work in all environments. In my research I try to understand if it can be used and what should be the proper way.

With this platform I hope the quality of patients' life improve, by giving to clinicians a new tool that can provide them an easy way for knowing how was the patient's status outside controlled environments and promote the relationship between patients and clinicians.

1.4 Approach

The main concern here is all about improving the wellness of the Parkinson patients, for that purpose we provide newer ways of obtaining information by giving new tools to clinicians to help them to understand the individuality of patients.

The first step was to understand what the needs of clinicians were, so we started a partnership with CNS (Campus Neurológico Sénior) that gave us access to patients' data and clinicians' perspective. For understand how the actual assessment practices work we conducted informal interviews with clinicians and observations of lab assessments with patients. To summarize the needs of clinicians and what are their expectations we performed a focus group based on an open mind approach. Five clinicians discussed with us their ideas in the fields of devices, activities, and data. Having this in mind, together with the ideas of the research team and the analysis of related work we decided to develop a web application called DataPark.

DataPark is a platform with the purpose of helping clinicians obtain more information about patients. It has different perspectives: objective lab assessment, free-living objective data, and subjective data. Objective data is obtained with the usage of a three-axis accelerometer sensor (AX3). Subjective data is based on filling electronic diaries via a mobile application or IVR (Interactive Voice Response) system. These diaries are built by clinicians on the web application and can be applied in both ways according to each patient.

The data-driven consultation tries to give a tool for clinicians to have a more objective way of getting patient health status. It helps in lab assessment by giving a mobile application that guides through the battery of tests and together with the inertial sensor produces data that is automatically analyzed by the platform and generates a report. The free-living objective data is based on the inertial sensor and together with diaries and asking to the patient allows clinicians to get a better overview of the time outside controlled environments. Clinicians can generate a personalized report according to the needs of each patient or the analysis they want to perform.

Subjective data uses the electronic diary approach, but it offers different perspectives by using both IVR or mobile output for filling the diary. It allows clinician to generate a questionnaire according to each patient needs but also to reuse and apply them to other patients.

We choose an iterative and co-design approach where clinicians had a close relationship with us. That way it helps the process of deciding how the platform should be build, because we have fast feedback from the users. In addition to the iterative feedback received we performed two final studies that show the benefits and limitation of DataPark and gives new perspectives of future growing.

The interviews allowed to fill the gap between what we think and what really was the reality for them. The first focus group gives us a lot of information to work with. At the end of these initial studies, we have plenty of data to analyze and process to reach the main goals identified by clinicians. Here we decide some initial design goals and how technically it will be possible, for example we decide to go through the inertial sensor approach because there are a lot of work already performed in that area that can be used, also some main features were defined: having reports to visualize data and what kind of data we should focus on early development.

Each part of DataPark is now well defined and each member could focus on their own development. Subjective data for obtaining direct information from the patients, improving the compliance, and proving an alternative way using an IVR system to call patients and ask them questions pre-made by clinicians with an authoring tool to generate workflows.

Objective data in controlled environments to improve the actual process of gathering data and providing new ways of analysis with inertial sensors. Objective data in uncontrolled environments to give more data to clinicians and try to understand what really happens when patients are outside their scope. Reports of all the parts can be visualized but only the free-living allows to generate a personalized report. So DataPark is a web application with different functionalities and an android app to laboratory context

Finally, to validate DataPark two final studies were performed, but only for the objective part. The first had the focus in the clinical process with the help of the Android app and in the reports generated in both free-living and laboratory context. The last study focusses on the web application usage and how clinicians interact with the different options in DataPark.

Our main goal is to give clinicians new tools that they can work easier than the ones already exist that focus mainly in raw data. Our approach allows the access to data processed, analyzed and that makes more sense to them.

1.5 Contributions

- **A set of collected requirements in studies** with different people that deal with Parkinson's disease daily, doctors, therapists, and patients. Based on observations, interviews, informal conversations and focus group we can have a set of ideas, opinions, and different perspectives. That way we can define what is the real needs for clinicians to have better tools with the focus on improving patients' quality of life.

- **A data-driven platform co-designed with clinicians** that allows clinicians to have access to data from patients outside a controlled environment. Navigate throughout the data, applying filters and generate a summary report of the data. Creation of personalized reports according to the analysis needed. Giving the hypothesis of having a print version of the report to deliver to the patients and discuss goals with them.

- **A preliminary validation of the data-driven approach** as the solution to help clinicians in real-world environments. The platform was built with the focus on the users, having an easy navigation and features adjustable to users' needs. A collaborative design allowed to have an iterative development minoring the time for wrong design options by early testing with users.

- **A platform that is being used in a real environment** and is main tool for the physiotherapy assessments in CNS.

1.6 Communications

We were invited to participated in two events: The first CNS conference and *Encontro Ciências 2018*.

- **In the first CNS conference, named "*Será que a tecnologia pode tratar a doença de Parkinson?*"** we presented two topics. The first consisted in an explanation of our research with inertial sensors and subjective data in free-living environment. We show our research approach and how we think we can contribute with technology for improving the knowledge about patients. The second presentation was focused in clinical evaluation and inertial sensors could be part of this environment.

- We participated in ***Encontro Ciências 2018*** with one project presentation, named "Data-Driven Healthcare for People with Parkinson's", and a demonstration session, called "Using inertial sensors in the onsite and free-living assessment of Parkinson's". The presentation consisted in showing an overview of our research about Parkinson's. We explained the objective and subjective data collecting procedure and how all of this is integrated in the platform. The demonstration consisted in a showcase of DataPark, focusing in reports' data.

Chapter 2

Related Work

I reviewed work about how to get objective and subjective data to understand the opportunities and challenges of a data-driven consultation and how important a visualization can be to help interpreting the data. To learn what is used by clinicians I analyzed literature about patients' diaries and lab assessment.

Previous work has explored the usage of sensors and mainstream devices to collect objective data. With the increasing usage of free-living data, researchers have started to explore how to use it in a clinical setting (data-driven consultation). In this chapter, I review projects that used inertial sensors, in different body locations, to retrieve data from patients. Mainly is based on lab assessments that allow detecting physical activity, energy expenditure, gait analysis and freeze of gait. In the free-living context diaries have a limitation relating to missing information that can be fulfill by the usage of objective data. There are studies using inertial sensors that try to use the same mechanism of lab in free-living. However, not all kind of data is already validated mainly for the Parkinson Disease.

The usage of devices that already have other purposes like smartwatches or smartphones can increase the compliance and/or decrease the discomfort in using devices to collect data. Studies show that this can be an alternative way but there is the need of more validation mostly in the target population.

Data-driven consultation is an approach already in use at several years. However, there is steel a gap that differentiates the research from real-world environments. I explain in the different areas how is the state of art and their limitations.

2.1 Clinical Wearable Devices

In a laboratory context, patients often must perform exercises that are observed and measured by clinicians. Examples are TUG (Time-Up-Go), Balance and walking. Godfrey et al [11] explored how these tests could be performed and more more accurately measured using accelerometry. The main goal of the study is to validate the use of accelerometry by comparing it with manual recordings.

The HAP (healthy aging phenotype) [11] gives a series of guidelines of tasks that a Parkinson patient should comply. **Postural control** consists of five tests of 50 seconds each and showed some difficulty in the task to obtain more data its needed more investigation. **Locomotion** in a 4m distance at the participants preferred speed, the sensor had shorter durations comparing to manual recordings. **Endurance**, a two-minute walk, in which the objective is to walk continuously and in a fast rhythm without running, the algorithm used overestimated step length and the total distance walked. **Lower limb strength** consisted in a repeated sit-to-stand-to-sit two times, the accelerometry had shorter duration compared with manual records. **Lower limb strength and locomotion** is a TUG (Time-Up and Go) performed three times, there were no main differences between manual and accelerometer. Results showed that in general no main differences were detected between manual and accelerometry recordings in most of the tests, so the accelerometer can be an alternative to measuring physical activity.

It is also important to understand other types of events to detect and quantify them. With the increased use of wrist-worn devices it is also relevant find out if it can be used. Mazilu et al [19] tries to find a correlation between wrist movement and freeze of gait in Parkinson disease (PD). The task consisted of performing diverse types of walking in a laboratory pre-designed to provoke FoG using an inertial sensor on the wrist. Statistical features (mean, standard deviation) from gait and freezing index are used to detect real-time FoG, but in the wrist was discovered that during FoG events accelerometer and gyroscope data have higher statistical features when compared with the rest of walking. So, the results showed that different subjects have different patterns during FoG, and also demonstrated that wrist devices can be used to obtain relevant information from patients.

Figure 2.1: A subject wearing the ETHOS IMU, an accelerometer (Mazilu et al[19])

There are more devices used in a lab context, like finger inertial sensors that can be used to obtain spatiotemporal kinematic parameters. Milica et al [8] uses a similar device to compare patients with Parkinson's Disease (PD), progressive supranuclear palsy-Richardson syndrome (PSP-R) and multiple system atrophy of Parkinson type (MSA-P). Each participant used two inertial sensors and was asked to repeatedly tap the index finger and thumb as rapidly and widely for fifteen seconds in three consecutive trials. The results showed that PSP-R had the highest cadence but mean duration per cycle was shorter compared to PD. So, there are many other devices that can be used to obtain valid data from patients to help clinicians in better understanding the state of disease, how patients feel and what are their evolution over time.

More recently, the use of inertial sensors for monitoring people with limited mobility has been increasing but is also necessary to focus on detecting activity. Nguyen et al [21] proved that this can be achieved by automatically recognize sitting, standing, walking, and turning. Each participant performed two TUG tasks equipped with seventeen inertial sensors. Standing (rise from the chair) and sitting (sit down on the chair) were detected with the acceleration of the trunk, to differentiate one from another the time derivative of the acceleration on the thigh was used. Turning was detect through angular velocity (AV) of the trunk and the AV of the head was used to verify the veracity of the turning and his direction. Walking was detected by using a five hundred millisecond window to verify the oscillation in the AV of the hip. To verify the accuracy of the algorithm manual recording were also performed to compare the timestamps on what activities have been happening. So the study aims were accomplished and it was able to show that inertial sensors can be used to obtain not only information about the patient status but also recognize some daily activities that can be important to better understand how is daily lives, of course this test was only performed on a controlled environment and in free-living it has some more obstacles to overcome that is outside the scope of the study.

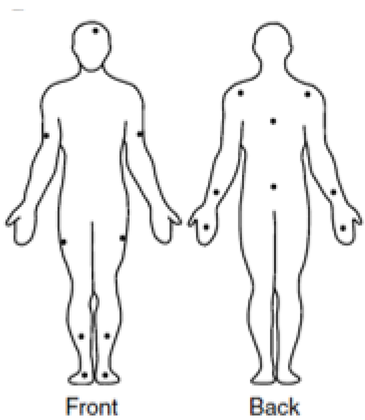

Figure 2.2: Each one of the used sensors and their locations (Nguyen et al [21])

In 2016, Del Din et al [7] conducted a study to find an explanation for poor agreements of asymmetry and variability, and validate the remaining gait characteristics by comparing Parkinson's Disease (PD) with healthy control older adults (HC) and laboratory reference. Participants wore an accelerometer-based device (Axivity AX3) to complete a task of walking at their choice speed in a ten meters distance. The analysis was based on a set of algorithms applied on initial contact (IC) and final contact (FC) events obtained with the help of wavelets and the inverted pendulum model. For validation, the results were compared with laboratory reference of GaitRite, a highly precise pressure mattress [7]. It was proved that is possible to use accelerometry to obtain valid gait characteristics, however because of different types of gaits do exist and people walk at their own speed some more validation of the robustness for these algorithms is needed.

Figure 2.3: GaitRite(left) (Del Din et al [7]) and Axivity Ax3 (right)

The increase of wrist-worn devices allows a diversity of characteristics such as gait, Cola et al [4] tries to obtain gait characteristics in an exact way with wrist-worn devices having an accelerometer. The technique uses a machine learning approach where the smartphone works as input data to confirm if the results of the wrist are good. An algorithm was developed for being able to obtain gait segments and results show that is an approach which can be used to obtain gait characteristics, however, it must be tested outside a controlled environment.

2.2 Mainstream Devices

Over time, new devices appeared and became more accessible and many started to wear them. These devices have the same capabilities as the clinical wearable devices, namely, they have an accelerometer and some of them also have other sensors. The main reason for these devices to be so important is that most people wear them in the daily life, so it will be easy to record data from them, it will be just asking people for permission.

In 2017 Barret et al [2] did a study with the purpose of validating the use of a bracelet for clinical purpose. The device was Fitbit Flex, the most popular in wearable activity tracking monitor, a small wrist-worn pedometer that provides measure of steps per minute, METs (Metabolic Equivalent of Task) and a Fitbit proprietary Intensity Score (is equivalent to the modified Freedson VM3 algorithm) that contains levels of activity like sedentary, light activity, moderate and vigorous. To validate the use of Fitbit device the ActiGraph GT3X (one of the most used and validated devices in accelerometry) was used to compare the results obtained. For each subject, a set of bouts was found in each data source, ActiGraph Freedson (AG), Fitbit Intensity Score (FB) and modeled Fitbit Freedson (FF). Fitbit is worn on the wrist that is more liable to have more movement in a day compared with the waist, so it is expected that the wear location influences the number of bouts per day by a subject and the duration of those bouts. However, AG was unable to identify some of the diary reports bouts comparing with FF and FB, suggesting a better sensitivity of Fitbit.

Figure 2.4: Fitbit flex (left) and ActiGraph (right)

Another study more focuses on how a smartphone can be used for detecting and monitoring Parkinson's disease (PD) symptoms were made by Arora et al [1]. Some pathological changes like motor symptoms, voice production (microphone), posture and gait (accelerometers), tremor (finger tapping tasks) and cognitive performance (reaction times) can be easily archived with a smartphone because they have built-in voice recorders, accelerometers, and touch screens. Each participant had a smartphone with Android OS and the applications needed to perform the task. Participants must perform five different tests four times a day. **Voice test** because voice impairment is one of the earliest indicators of PD consists in saying 'aaah' for as long and steadily as possible. **Posture**, standing upright unaided for 30s. **Gait** walk twenty steps forward, turn around and return. **Finger tapping** to evaluate arrhythmogenesis, consisting in tapping the screen alternately keeping a regular rhythm. **Reaction time**, press and hold/release the on-screen buttons as soon as it appears/disappears. It was clear that smartphones should and can be used to accurately differentiate individuals with PD from others and potentially predict the degree of the disease, also it is possible to record accelerometry continuously in the background to give others measures like energy, gait or physical activity level.

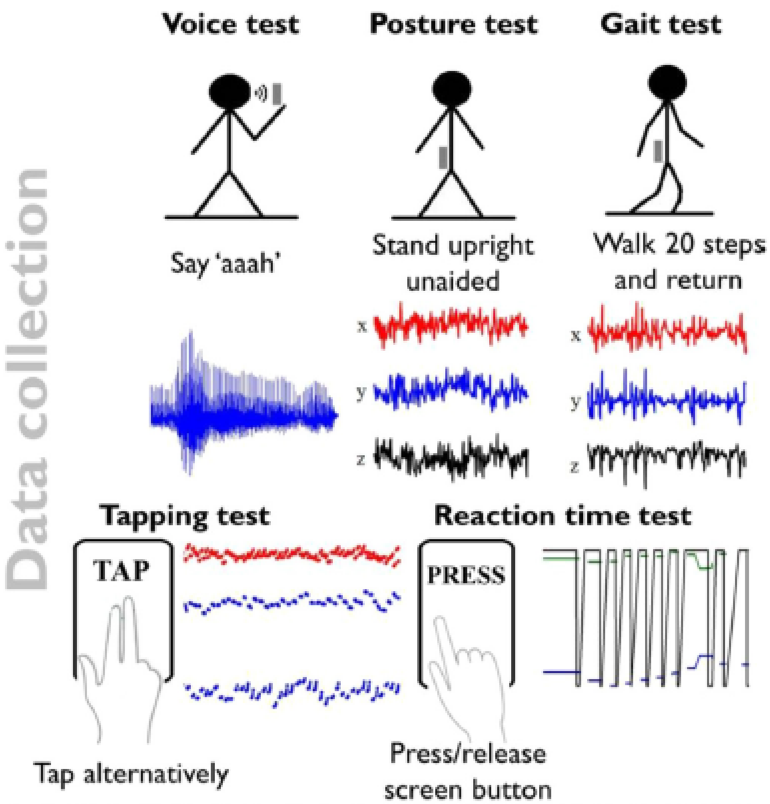

Figure 2.5: The battery of tests used used in the study (Arora et al [1])

Tremor is a rhythmical involuntary continuous oscillation of a body part interfering in the control of motor movement like Woods et al [24] explains in the study it influences Parkinson's disease (PD). The aim of the study is to prove that smartphone-based applications can be used in clinical environments and are an easy way to help people with limited access to medical staff. The android application consists in recording accelerometer signals and then processed them with wavelets (Discrete Wavelet Transforms) obtaining the tremor values from the acceleration of hand movement (extracted from the frequency of the signals) and the energy that allowed to measure the relative tremor frequency strengths and predominant tremor frequency. Participants were asked to perform six tasks for each hand to measure the levels of attention and distraction. **Tremor with eyes open (Vis+)** requires the phone to behold in one hand with the eyes open and focus on a distant point. **Tremor with eyes closed (Vis-)** the same as above but with eyes closed. **Tremor while attending to the active tremor hand (Bubble)**, observe the hand holding the phone and stabilizing a small bubble within a circle template so that the bubble stayed within the circle. **Tremor while paying attention to a laser target at 2/1 meters (Laser2/1)**, looking to a 100/50 mm circle on a wall two/one meter away while keeping the phone tight with a small laser light to the circle. **Tremor while not paying attention to the hand but while counting backward by 3 (Counting)**, requires holding the phone while considering the distance and counting aloud backward by 3 from a number between 50 and 100. The results showed that the distraction task (Counting) has a significant impact on PD population, having a higher tremor power comparing to the others. In smartphones, there are some challenges that can limit what we can do, related to the amount of memory available to process. However, the study once again showed that smartphone can be used as an alternative for medical context allowing an easy way of getting data from people's phone and that can be used and analyzed to provide useful information for both patients and clinicians.

With the increased use of smartwatch, there is needed to confirm if the measures given are correct, namely the step count algorithm. Genovese et al [10] performed a study to validate the possible use of smartwatch to apply step counter algorithm. This type of device generally has a high compliance, although there is a problem of reliability of measurements, wrist gesticulation, and variability are challenging. Participants wear a Gear 2 smartwatch on the wrist and a commercial step counter (SC) on the waist. The tests consist of seven tasks: walk-turn-walk, slow and steady walk, variable-speed walk, very slow walk, jog, going up-and-down stairs and in-home task. Results showed that smartwatch tended to undercount steps, however in both walk-turn-walk and the in-home task was a better performance than the waist device. The study gives an overview of how a wrist-worn device, namely a smartwatch, can be used to recall measures that can help both patients and clinicians. Although there is a limitation in the study related to the participants' state because none of them have a disease, so the process must be tested to validate is used in a medical environment.

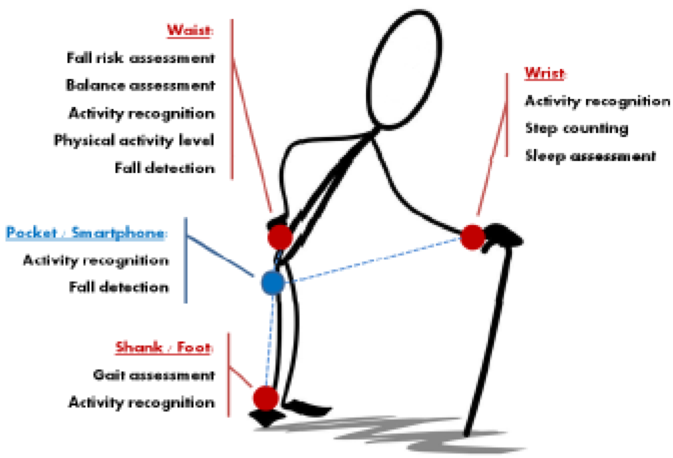

Figure 2.6: Example of possible sensors location and their output analysis (Genovese et al [10])

2.3 Challenges of Free-Living Assessment

Clinicians need to know what happens with the patient outside the appointment, so the easiest way of archiving that is by asking the patients how they felt. Hufford el al [15] explains that recall is unreliable, so if physicians only obtain information in conversation with patients it can be lost a lot of relevant data that would be helpful for the clinician. One way of achieving it is by using paper diaries that allows people to describe how they felt in a period closer to the events. In this study, paper and electronic diaries are compared with the goal of quantifying compliance with paper diaries. Participants were asked to answer a questionnaire three times a day (morning, afternoon, and night) along a period of three weeks, some used an instrumented paper diary (IPD) others use an electronic diary (ED). Two types of compliance were measured: reported compliance, the one written by the patients on the IPDs and actual compliance, the one recorded by the EDs. The EDs only allow being written in a thirty minutes window, having an alarm at the time that the diary should be filled and on-screen feedback if the reporting was missed. The results show an interesting thing about the paper diaries, although there is a high reported compliance the real one is much lesser, showing that some of them are falsified. On the other hand, the ER has a high compliance that can be trusted. Problems related with the veracity of the reports, because the target of the diaries are people that much of time can forget things or not know for sure what they have been doing or how they feel, so it must be another way of tracking what people have been doing in free-living.

Figure 2.7: Paper diaries (left) and electronic diaries (right) (Hufford el al [15])

Essential tremor (ET) is an example of how important is to not only monitor patients when they are in a clinical environment but also in their homes. Pulliam et al [22] explains that although there are ways of obtaining data from ET patients in the lab environment and rating scales to classify the measures obtained, it always requires the presence of a clinician to help interpret the results obtained. There is a need to monitor patients' activities in home environments to better understand how the disease progression is. Participants of the study must wear a motion sensor on their index finger of the more affected hand and perform three tasks (postural, rest and kinetic tremor) one time in a ten hours period of the two days. Results proved data collection on the home environment can be very helpful, not only for clinicians (because they can better understand how the evolution of the patients through the day is and outside a controlled environment) but also for the patients, because in this way they can be monitored without changing their routines.

Figure 2.8: Kinesia HomeView, a finger sensor and its dedicated application

In 2016, Del Din et al [6] explains the benefits for both clinicians and patients in using remote monitoring with wearable technology and connected devices (WTCD). Clinicians have a new way of obtaining relevant data from their patients in the places they spend most of his time where some behaviors are more likely to happen. The focus is to understand the role and benefits of free-living monitoring, validate the utility of WTCD in monitoring clinical features to PD and critical challenges to its use in free-living. Relevant features that can be extracted are: gait, FOG, falls, physical activity and sleep analysis. However, for the use can be extended to clinical environments it is needed to define what clinicians really want, validate the data in real-world and overcome WTCD challenges.

Later, a new study from Del Din el al [5] tries to validate the collection of gait characteristics in a free-living environment by comparing with lab results. Each participant wears an accelerometer-based body-worn monitor (BWM) and an Axivity AX3, to perform four walking trials over ten meters at their choice speed to obtain laboratory data. The free-living data was obtained after by participants wearing BWM for one week. Free-living can be particularly challenging and difficult to validate data because is not easy to know what really happens. However, BWV can be used to obtain gait data in free-living context, but more testing is needed so the data can really be trusted.

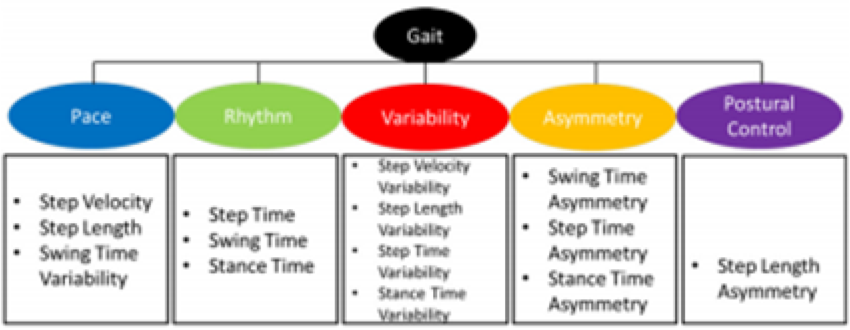

Figure 2.9: Core of gait characteristics (Del Din el al [5])

Another study from Hickey et al [14] tries to validate the use of accelerometry to obtain data from free-living environment, but only focus on step counts and walking bouts. Participants wear an Axivity AX3 on the lower-back for one hour in two different days and must perform their normal daily activities. Although the algorithm was affected by the false positives it showed a good correlation in both step and bout count, and it was even higher when cycling was removed from the analyses. The study is another major step in trying to validate the use of body-worn devices in free-living, however further validations are needed for allowing the use in clinical environments.

More recently, Doherty et al [9] showed the use of accelerometry to retrieve physical activity measures in a wrist-worn device, because it claims waist-worn devices and recording during awake-time only will result in loss of data. An Axivity AX3 accelerometer was used to record data from physical activity. To process and analyze the data a set of algorithms was used, like calibration, filtering, and vector magnitude. This big study allows not only to validate the use of a wrist-worn device to collect accelerometry data, could later be used to obtain physical activity measures but also other types of analysis (like sleep). Data from free-living environments is a valuable tool for both clinicians and patients. Clinicians can have an objective overview that complements the subjective data obtained by talking with the patient, so it proves that both objective and subjective data have their role for better understanding what happens outside the controlled environment and in such cases, is where the relevant information happen. Patients can also be provided with more information that they already know and can understand how they fell by completing what they know with more objective data. However, must more data can be collected from the free-living environment. A complete sleep analysis, an overview of several tasks performed (drink, eat and many others) and of course detect and provide solutions when the symptoms happen, this can be performed remotely some of the interest for the patient with always the help of the clinician.

2.4 Data Driven Consultation

Data is important in helping the clinicians to have a fastest and better way of understanding what is happening with the patients in a controlled environment (laboratory) and in free-living.

Data-driven consultation gives support to clinicians during their appointments with patients. It as the purpose of increasing the knowledge by giving tools that should facilitate clinicians' job and do not disturb in a negative way the current process. Data-driven is been used for clinical purposes at a long time, but like everything it as evolves over time, in 1999 Graham et al [12] used a data-driven approach to study diversity in Idiopathic Parkinson's Disease (IPD). There was some evidence that the disease can be categorized into distinct groups: the existence of certain motor symptoms, the age at which the disease began, cognitive capacity and the depressive symptomatology of the patient.

For each patient, to obtain more knowledge there was used a measurement set: motor functions, according to the Unified Parkinson's Disease Rating Scale (UPDRS) to rank the severity of IPD motor symptoms (tremor, rigidity, and bradykinesia). Mood and affect, given by the Beck Depression Inventory expressing the impact of depressive symptomatology. Global cognitive function, using the Blessed Dementia Scale Information-Memory-Concentration Test. Visuospatial function, that measures the capability to distinguish between known/unknown patterns and spatial positions, using The Pattern and Spatial Recognition Memory subtests from CANTAB (Cambridge Neuropsychological Test Automated Battery). Executive function be applying the CANTAB SWM (Spatial Working Memory) subtest and the DO (Digital Ordering) paradigm. Demographics, to known patients' personal information, like when disease as started, disease duration, medications, and complications because of the disease. The UPDRS activities of daily living were included to understand the degree of influence of the disease in the daily functioning.

With the help of the cluster analysis, there were five final groups that captured all the different symptoms. Data-driven has a key role in analyzing more rapidly the data and allowing to obtain a comment and easily perceived information about the patients.

Later another study to define clinical diversity in IPD, made in 2004 by Lewis el al [17], used data-driven to try to group and understand better the differences in early clinical stages. The new study is using again the cluster analysis method, so each patient can only belong to the group of its most predominant characteristics. Groups of patients with the same characteristics allow clinicians to apply similar treatments but paying attention to individualities of each person. The cluster analysis can give many different results based on the variables used and the number of cluster solution (categories) that we want, so to enrich the study test was performed with two, three, four and five cluster solutions, also not all variables were used to allow a post hoc comparison confirmation of the cluster obtain. Finally, all the different cluster solution size has similar groups, the one with four clusters was the one that allows manifesting the level of heterogeneity needed to understand the different characterizes of the group of patients, like younger onset, tremor dominant, non-tremor dominant, and rapid disease progression. These new ways of exploring the data that are important for helping clinicians making a more guided decision and help in adjusting the optimal treatment or understand what type of patient the clinician have. Each patient has his/her one singular characteristics, so the groups determinate by the cluster analysis should be used only as a manner of getting more information, and mainly to get it in a fastest and concrete way.

Data-driven can be applied for knowing the effects that medication can have prior to is used in a real-life situation, like Haefeli et al [13] explains in the study. An experiment in rats has been performed to understand the impact of some medications in treating traumatic brain injury, to better perceive the data being analyzed a data-driven method was applied. To analysis, the data different methods were applied, including a data-driven approach allowing to compute and get the fastest result of the data by applying the non-linear principal component analysis (NL-PCA), that used optimal-scaling transformations. A new way of using data-driven for helping to better and easily understand a disease or how it can be treated, the results showed that clinicians could obtain information that in another way would be most more difficult, so the main reason for applying data-driven is to improve the tools that clinicians have for treating patients.

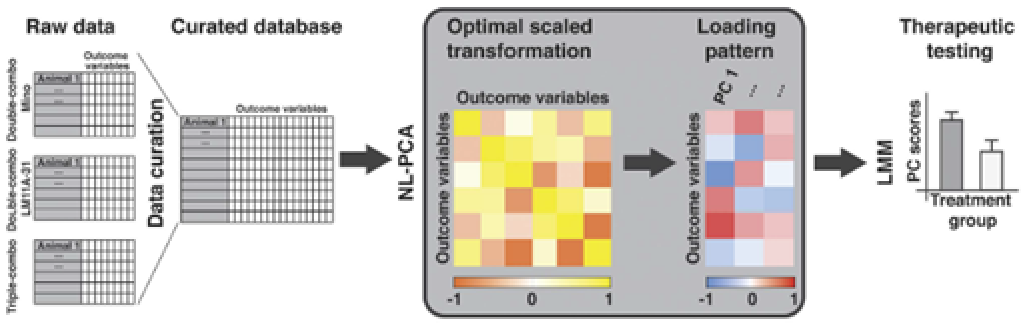

Figure 2.10: An example of the process in the data-driven application (Haefeli et al [13])

More recently, data-driven has been used with a greater focus on visualization. In 2017, Kim et al [16] perform a study that focuses on developing a data-driven interface with the help and contribution of the ones that will use it, the clinicians. The challenge here is to build a platform that as a real impact in changing the environment where it should be used, for example in appointments doctors have to do a lot of tasks at the time (talk to the patient, perceive their symptoms and write all things that matter for reporting). This new tool cannot be just one more thing to the clinicians deal with, the main purpose is to facilitate is work so as to be something that they easily interact and can gather information having a real impact at the time that is really needed. In summary is perceived that a data-driven consultation has must benefits for the doctor and the patient, improving the relationship between them, providing objectives to the patient and allowing the clinician to have a rapid and more informed overview of what was missed outside the appointment. Much is yet to be made in this area to allow not only a better integration for the clinician needs but also considering what the patient wants.

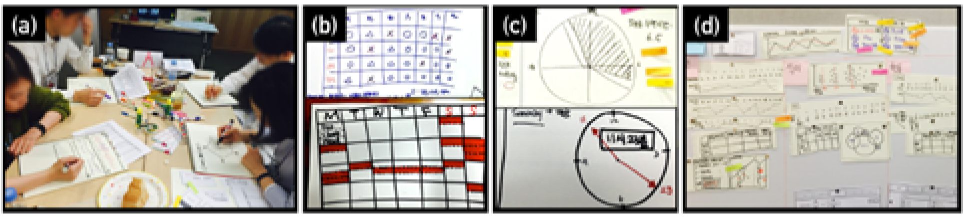

Figure 2.11: The process of designing a data-driven solution a) workshop of sketching ideas. b) an example of sketches c) another example that gives new ideas d) an overview of the paper prototype (Kim et al [16])

Like Mentis at al [20] shows up having a tool that provides useful information can guide clinicians in identifying trends, outliers and ways of improvising patients' lifestyle. Patients can explain some of their barriers and difficulties. The study consists of each participant wear for a period of four weeks a Fitbit Zip step-count sensor. The output was a set of charts that show both daily and weekly visions of how much steps patients are taking. There was a real guide for the discussion in the appointment. For clinicians, the goal was to define a walking strategy to increase the physical activity of each patient, by understanding what their current pattern were and causes. The patients could explain what really happen and could think in a more concrete way what are causing the values of steps archived. This approach as the advantage of guiding the appointment to center the discussion not only in subjective data but with objective one that can open new perspectives for discussion. Although is as are downsides, for example, patients are mainly guided by clinicians' analysis. Some alternatives appointed are creating different views for patients and clinicians, being able to watch at the time the data and interact with it.

Text-based documents can be a useful source of information for clinicians know the clinical history of patients and answer the questions in consultations. Sultanum et al [23] did a study where tries to address the problems text documents can have and how a visualization approach for fulfilling it could improve the way interaction between clinicians and patients happen. For that purpose, an application was created having its focus on the clinicians' text notes completed with sentimental text analysis and some visualization aspects. Results showed that text and visualization are similar, but the quality of answers are bigger in visualization. In summary, the study gives a series of guidelines on how to design a data-driven application centered on user expectations and needs.

2.5 Discussion

In laboratory environments the devices being used to obtain data from patients have been changing throw the years, the more practical is the accelerometer. However, there is still huge use of older devices, because of the unfamiliarity with accelerometry devices or not enough validations of their use. Mainstream devices, mainly smartphone and smartwatch, can be a good source for retrieving information from patients, because they are heavily used and have a set of incorporated sensors (accelerometer included) that can provide rich information. Although, there is still a lack of validation of its use as a clinical tool and reliability must be assured by guaranteeing that patients really use it. In free-living there are many challenges to overcome, first its related with the compliance and how it may be possible to obtain valid subjective data from patients, improving the compliance and assuring diaries are filled. Another obstacle is how to retrieve objective data, some recent studies have validated how data should be obtained there is still some validations related to specific metrics. The main challenge will be related to finding a way of obtaining the data and assuring patients' comfort. Data-driven is an approach for supporting clinical matter improving the tools available for clinicians. One of the most interesting topics is how data should be presented to facilitate the analysis and improve the knowledge about patients. Despite some tests already been done there is much more to improve in this area. Both clinicians and patients must be part of the design process to really understand what they need and being able to develop a data-driven interface that really makes the difference. An easiest, fastest, and precise way of showing patients' data should be the main focus on free-living development.

Chapter 3

System Design

The goal of this research is to support clinicians with new tools focusing on easy interaction and provide new ways of analysis for new and already know data.

The method chosen was an iterative design. It gives the opportunity to minimize potential usability problems by testing soon with new users, on the other way users make part of the decision process so some problems will be soon discovered, and new solutions can be applied before any need to develop.

This chapter gives an overview of the design process for the system. Based on Literature Review and preliminary discussions with clinicians it explains some initial studies performed with target users. With all the information collected the system requirements and use case scenarios were defined. Also gives an initial approach to the interaction the users have with DataPark.

3.1 Exploratory Studies

Before I started my research there were preliminary conversations with a neurologist, led by my advisor, that gave the first draft of what we now call of DataPark. For the neurologist there was the need of getting more tools, mainly based on objective data, for understanding what happens with patients outside appointments. Although he already had contact with data that gives metrics about free-living, he could not perceive or analysis that data.

When I started, the first step was collecting as much information as I could. For that purpose, I did literature review and understand with the potential users of the platform what were the real needs.

Next step was informal interviews with the neurologist and a therapist. Based on what I have collected from previous research, I introduced my ideas for the platform and listen what clinicians have to say about it. The focus was to understand if my vision was aligned with their real needs.

For summarizing and obtain more opinions we conducted a focus group with potential users to define some design aspects and what kind of data was relevant to be present in DataPark.

3.1.1 Interactive Design

The first prototype of DataPark was developed before meeting with the users. Its purpose was all ready to show some capabilities that can be offered, it was based on the literature review and some internal discussions in the team. This prototype included minimal resources and was mainly focus on the basic free-living analysis and minimal interface to interact with the data.

In the first informal interview, first we discussed with a neurologist and a therapist what they consider important to obtain information about the patients and how can we make it possible from the technology perspective. So, after understanding some of their needs, we explained our idea of the platform, in the three different perspectives (Free-living, Clinical and Subjective), and we tried together with them to converge in what should be the first version of DataPark. Finally, we showed our prototype without an initial idea and received immediate feedback of what should be improved, like the possibility of exporting data outside the context of the platform.

Later on, we were given the opportunity to watch therapist intervention with a patient. It consisted in a set of tests performed by the patient that at the end were expected to give an overall overview of patient's health status. Also, the patient used the sensors like many other already use and the data allowed us to give other types of analysis. For us, it was a wonderful opportunity to watch and interact directly with him, observing difficulties and limitations. It also gave a perceptive of how the process of is evaluating a patient and what are the difficulties that therapists must face, like paying attention to tasks being performed and mainly to the wellbeing of the patient.

These two meetings with potential users and patients gave the perspective that we needed to better understand what the real needs were. Together with the literature review gave me a clearer image of what should be the contributions that I could try to achieve in giving clinicians better tools to help understand how patients behave at home.

3.1.2 Focus Group

We had a focus group with potential users to try and capture a broader perspective of what were their needs.

3.1.2.1 Research Goals

- Know what type of data is relevant to collect in free-living context
- Understand how to collect objective data in free-living

- Understand how data should be presented to users
- Identify the main topics that should be presented in a report, that should address both clinicians and patients' point of view

3.1.2.2 Participants

Five participants took part in the meeting. It was a heterogeneous group that allowed us to have a different perspective of people that work with Parkinson's diseases. It was composed of one neurologist, two physiotherapists, and two nurses.

3.1.2.3 Procedure

This study was conducted as a participatory design session with stakeholders. In the session, participants were engaged with the researchers in defining the workflows, data, and their presentation, in the data-driven platform. The focus group consisted of a set of different boards (Devices, Activities, Data) that should be filled with information relevant in each one by the participants.

First, we start with Devices and give participants an option to think about all the possibilities that could be used to collect data. Secondly, we present out the main device, the AX3 device, and ask them what kind of activities are relevant to gather information about patients. Finally, for each activity or group of activities, we asked to define data that may be helpful to have at their disposal. In the end, we challenged each of the participants to list or draw a possible free-living report and enumerate some important points that should be part of it. [Script of the session is in Annex A]

3.1.2.4 Findings

The study gave us the opportunity to understand potential uses of the platform. Due to our purposeful open perspective, we encountered several suggestions that would unfeasible but are still relevant to inform future research. Our main goal was accomplished, and we generated a good discussion with several topics to analyze.

3.1.2.5 Consolidation

After the focus group presented it now time to reflect on all the information obtained. Looking for the goals established at the beginning we can say that a lot of information was collected. However, it was needed to analyze it and select the ones that were more relevant for users and that could be technological executed. The idea was to use the concept of boards but in a digital approach that will speed up consolidating data. For that purpose, an online tool called *Trello*[1] was used to recreate all the boards in paper format,

[1]https://trello.com

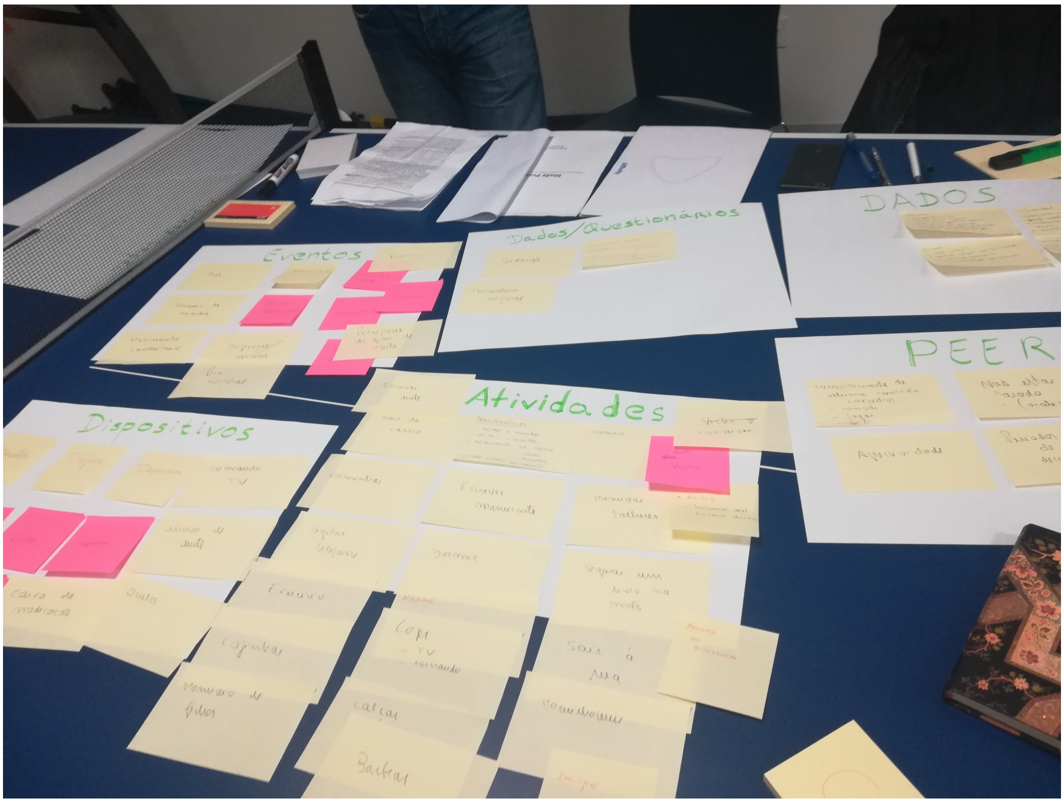

Figure 3.1: Focus Group general view of the session

so that we can easily look, select and discuss all the different possibilities. We decided to share this digital version with all the participants in the study and with other possible stakeholders. It was not only to show some of our conclusions, but mainly to have an interactive process of gathering more data. A new board called Scenarios was created with the purpose of capturing real-world scenarios that could happen with Parkinson's disease, so we could retrieve more data from those examples. Finally, we group all the information from digital boards and together with the example reports give me the information I needed to understand and transform the initial prototype in something that is even more aligned with their needs.

3.1.2.6 Results

The devices, activities, data, and reports are all from the focus group. Scenarios was posteriorly created in the digital version and filled by clinicians. [All the boards, digital and paper versions, are available in Appendix A]

Devices

By opening the discussion to all the possibilities, is does not matter if it is technological possible or not, we gather a huge diversity of devices. From the more possible like inertial sensor to other like the tv remote.

Activities

In the activities section again a bunch of different options were selected. Here there are very well know activities (in research perspective) like sit, stand, walk, sleep. However, daily life activities like cook, shave and dancing were also mentioned, that in a research perspective are remarkably interesting try detecting them, but there is not much work, especially validated, about that.

Data

For each of the activities, according to both participants and researchers, we selected sleep and walk. In these activities we explored the possible data to collect from them. Again, there were already some of the data not well validated like volume during sleep and an agility global measure. However, wake ups and transitions during sleep and gait analysis have studies that explore that.

Reports

At the end, all participants fill, by drawing or texting, what they found that a report should be. Sleep, gait, and physical activity were referenced by all the clinicians. Other data like balance, tremor, falls were also mentioned.

Digital Boards

We decided to add Scenarios featured on digital boards because it captured much information and for clinicians is easy to think in real world scenarios. For example, generate alerts for taking medication or when falls happen and the patient cannot rise automatic calls are made for the medic staff or family. The Data boards were increased with health data (height, pain, fall episodes, weight) and generic data (involuntary movements, daily life events).

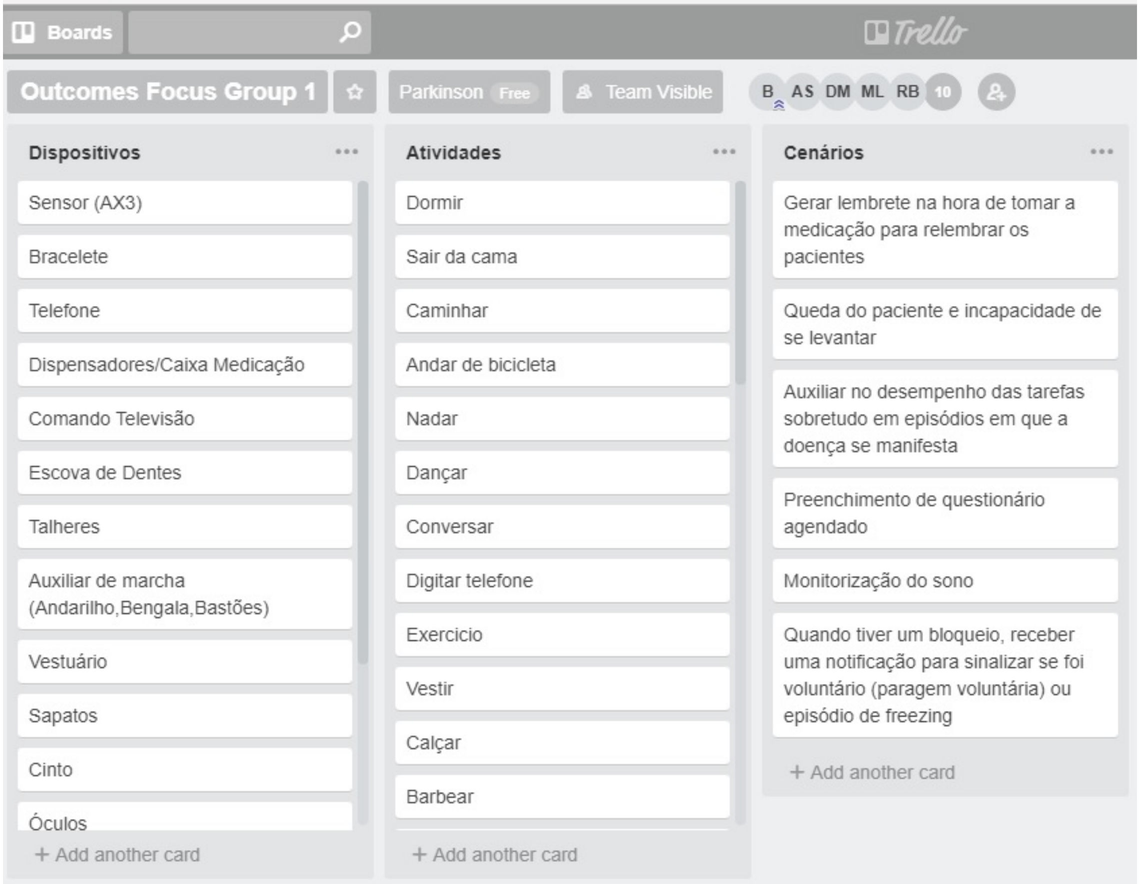

Figure 3.2: Example of the digital boards created

3.1.3 Discussion

We learned a lot with the conversations with clinicians, observations of the process of evaluating a patient, all the rehabilitation weeks we had collaborated in and the focus group. The initial conversations had the purpose of understanding what the clinicians' needs were and where could technology give their contribute. This includes the first discussions about the concept of giving clinicians tools that help them doing their job. Also, the informal interviews with clinicians gave a more detailed perceptive of where we could be useful. The focus group was important for summarize all the collected information. By opening the discussion to a broader audience, we gather a lot of knowledge about their expectations. Our purpose, in this initial phase, was to gather as many data as possible so we could have a picture of clinicians' ideas. At the end of this preliminary stage we had the need to organize our ideas based on all the data collected. That way we started to define how should the platform be.

3.2 Data-Informed Consultation/Assessment

DataPark is designed to be a simple, intuitive, and interactive web application to help clinicians better understand what the real needs of patients are, offer an objective way of looking at Parkinson's disease when they are outside the clinical context. The innovation here is how data is presented to the users with the main factor regarding the usability of the platform and the capability of creating and personalizing self-made reports for end users. I defined the normal procedure of how the system will be used dividing it into different steps.

1. Patient goes to an appointment with the clinician.
2. Clinician gives him a sensor to use until the next appointment.
3. Patient returns to a new appointment.
4. Clinician removes the sensor and uploads data to DataPark.
5. Clinician has access to a processed view of the data with useful information during appointments and understands what happened at home with the patient.
6. Clinician can generate, personalize, discuss, and give a report at the end to the patient.

3.3 System Requirements

Defining System Requirements is a crucial step to describe functionalities and how design goals should be applied. This section is divided into two topics: functional requirements (describe system functionalities) and non-functional requirements (describe system properties that should be guaranteed).

3.3.1 Functional requirements

User:

- Visualize data about sleep, energy expenditure and physical activity
- Provide an account for each clinician, that will share all the patients in DataPark.
- Create patients, guaranteeing its anonymity.
- Allow files of free-living to be uploaded and process them for future analysis by the clinicians.

- Generate a report based on the free-living file and provide an easy and fastest way of visualizing information.
- Filtering through data, allowing clinicians to analyze data on distinct levels.
- Personalize data present in the report, clinicians can build their own report.
- Generate a pdf report that can be saved or printed that should facilitate clinicians' analysis and be easily understood by patients.
- Allow editing patients information.
- Allow editing files additional information.

Administrator:

- Being able to access the same information as a common user.
- Manage users accounts, by changing users' privileges and delete accounts.
- Invite new users and manage the invite already made by the admin or other admins.

3.3.2 Non-Functional requirements

- **Availability**: The system must be available whenever necessary to not disturb the clinicians work.
- **Performance**: Response time should be short but it depends on the internet connection.
- **Privacy**: Data should be protect guaranteeing patients anonymity.
- **Data integrity**: The system must validate all the data being shown.
- **Documentation** : Help on navigation and provide user guides.
- **Portability**: The system must work on different devices and browsers.
- **Usability**: It must be easy for users to interact with the system.
- **Reliability**: The majority of the functionalities must work most of the time.
- **Extensibility** : Add new functionalities must be easy.

3.4 Use Cases Scenarios

DataPark can be potentially influenced by two stakeholders: clinicians and patients. So, for clarifying the requirements, a scenario will be presented. First, a scenario without the use of the platform is showed to illustrate how is the actual workflow of events in real life.

Free-living data without DataPark

Pedro is a 70 years old Parkinson's disease that lives with his wife, Maria, in Lisbon. He goes to an appointment with his doctor, Dr. Manuel, next Wednesday. Until then he must fill a daily questionnaire in periods of 30 min with questions about sleep episodes, and overall wellbeing. When he goes to see his doctor, he delivers the filled questionnaires and answers some more questions about how he felt. Pedro, somedays, forgot to fill the diaries so his wife Maria helped him later those days to fill them. Some of them he could not remember with certainty how his condition was, so he tried to give an approximate answer. Dr. Manuel tries to adjust the patient medication according to his stories and the exercises performed during the appointment. Although, Pedro is feeling good at the time, he had a tough time at home some of the days. Dr. Manuel schedules a new appointment for Pedro and gives him his new recipes. Pedro goes home, fills the new diaries, and returns to the next appointments. Dr. Manuel after seeing the answers tries to compare them with the previous and to have an overview of the how Pedro felt at home in the two different periods.

Free-living data with DataPark

Pedro is a 70 years old Parkinson's disease that lives with his wife, Maria, in Lisbon. He goes to an appointment with his doctor, Dr. Manuel, next Wednesday. Until then he must fill a daily questionnaire and use an inertial sensor. Questionnaires were previous scheduled by the doctor and consists on automatic calls in periods of 30 min with questions about sleep episodes, and overall wellbeing. When he goes to see his doctor, the sensor is removed. Dr. Manuel now have access about Pedro's days, both on objective data (sensor) and subjective (diaries). This leads to a discussion between them based on the comparison between diaries, sensor, and answer by the patient. Dr. Manuel have also requested Maria to annotate specific episodes, like freeze of gait or falls. This is done with a mobile application for relatives and allowed to obtain more information from a different perceptive. He now can prescribe medicines in a more informed way, because not only sees how Pedro performed some tasks at the clinic, but also see the fluctuations and have an overview of Pedro last week. Dr. Manuel schedules a new appointment for Pedro and gives him his new recipes. Pedro goes home and returns to the next appointments. Dr. Manuel can objective and subjective data with the last appointment. [The subjective data is part of the project but is outside of my research scope]

Chapter 4

DataPark

We developed DataPark for evaluating the impact of a solution for evaluation based on data. System requirements focus group and the initial conversations helped to clarify what kind of functionalities the platform should have. DataPark is a web application that uses a set of programming languages, such as Python[1], HTML, CSS, Java[2] and JavaScript[3].

The system has the focus on providing the best user experience for the users. In the background the data is processed and analyzed by algorithms. Although some of the algorithms can be applied also to the wrist for the scope of this thesis only the trunk sensor location was rigorously tested.

4.1 System Architecture

DataPark is composed of different components each one having its own role on the system. The first step is obtaining data from the sensor (Axivity AX3)[4]. For that purpose, the sensor must be connected to a computer, and with the help of a program developed by the sensor suppliers, OMGUI[5], the binary data (CWA format) can be downloaded to a local file. The CWA file have binary data that contains the signal, about the period of analysis, and some metadata.

The diagram 4.1 shows the different components of DataPark and the data exchanges between them. Main Module is responsible to receive the request from Front End and if necessary, forward to the respective module (Pre-Processing Module or Analyzing Module). Each one of the modules can communicate with the Database according to its needs.

The file must be uploaded in the system, using the Front-End interface. After that, the Main Module receives the request and forwards to the Pre-Processing Module. In this step, the file is converted in CSV format and occurs a processing phase, to get vm (vector

[1]https://www.python.org/
[2]https://www.java.com
[3]https://www.javascript.com/
[4]https://axivity.com/product/ax3
[5]https://github.com/digitalinteraction/openmovement/wiki/AX3-GUI

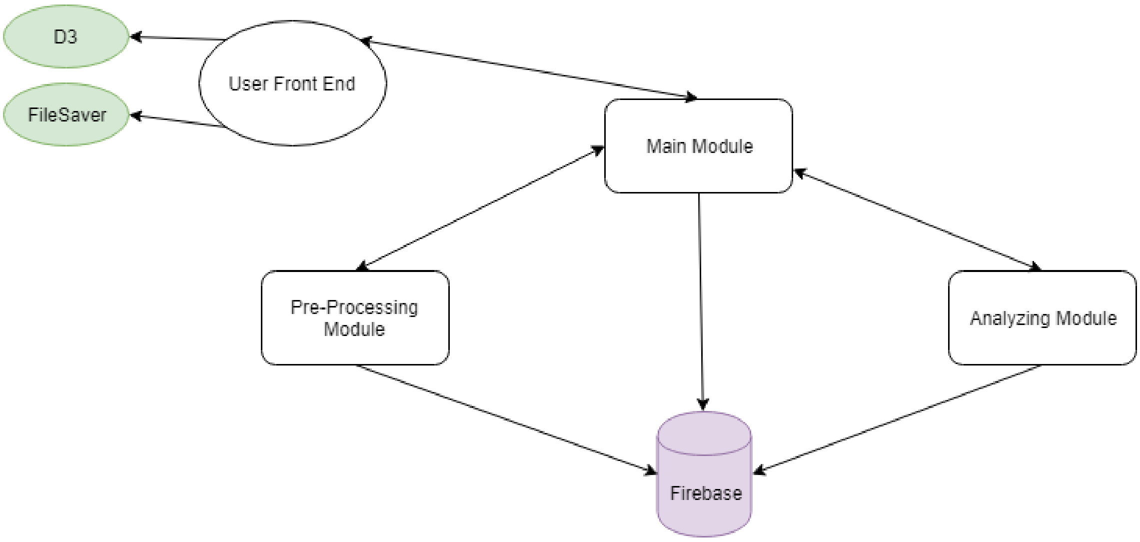

Figure 4.1: Datapark Architecture

magnitude), timestamp and the value for each axis (x,y,z).

When a file is requested for analysis, the Main Module forwards to the Analyzing Module. In this step, the data for building the report data is processed and sent to Front-End.

4.1.1 Components

DataPark is a web app composed by Front End, Modules, and Database. Front End deals with the users' interaction with the system, giving the ability to navigate and explore through up the data. The database is divided into data and files storage. Much of the work is carried out by different modules that have different responsibilities in responding to the request, processing, and analyzing the data.

Main Module

Main Module is the central component of the system. It receives the requests from Front End and forwards it to the respective module if needed.

It is responsible for most of the system functionalities: Registration, Log in, Manage Users, all the patients related features (create, edit, select and delete), and edit and delete files. If any of these features need to access database for insert, delete or edit information, the module controls the operations.

When is a registration process the module handles all the aspects related to email sending.

Pre-Processing Module

Pre-Processing was implemented as a Java Rest API. I decided to build it like this for not be dependent of how the system works. That way it can also be reused in other systems. The API consists in two endpoints: */epochDecimal* and */epochNormal*. The */epochNormal* is used for processing files that will generate epochs in seconds (at least one. The */epochNormal* is used for processing files that will generate epochs under one second (that means in milliseconds). Both needs as input the name of the input and output files. The */epochNormal* needs one more parameter, the epoch period wanted. These are implemented in separate for simplifying the calculations involved in processing milliseconds and seconds. In each one of them the binary file is read according to the stipulated by the suppliers of the sensor. This happen because these is not a normal binary file, it has its own

This module handles the transformation of the input file, in CWA format, to an output file, in CSV format. The output has all the information needed for the next steps, such as the timestamp; the value for each axis; the vector magnitude; the standard deviation; and the combined standard deviation.

The CSV file together with the uploaded CWA file are saved in the Firebase storage. This allows to be used in the next accesses.

Analyzing Module

The Analyzing Module have the task of producing summaries for each of the relevant categories of analysis (energy, sleep, physical activity). For that purpose, uses the CSV file for getting the raw data and applies algorithms for obtaining the summary data.

This module is only implemented in python. It is composed for different script for each one of the categories. The final output consists in identifying each entry on the CSV file with the necessary information for each category. Physical activity identifies the type of activity performed in (sitting, standing, lying and walking). Sleep classify the different positions in sleeping (prone, supine, side right, side left). The energy, at the module's level, only consists on the vector magnitude.

Finally, all this computed data is sent to the Front End by the Main Module.

Visualization and UI

Visualization and UI is the featured leading directly with user interactions. To deal with it, a set of different libraries are used. The default report is built with the information received from the Main Module. Still, is necessary to applied filters for obtaining the different summaries per category. [More on that in implementation section] D3[6] is a library used to create charts that allow to choose from a set of templates, customize it

[6]https://d3js.org/

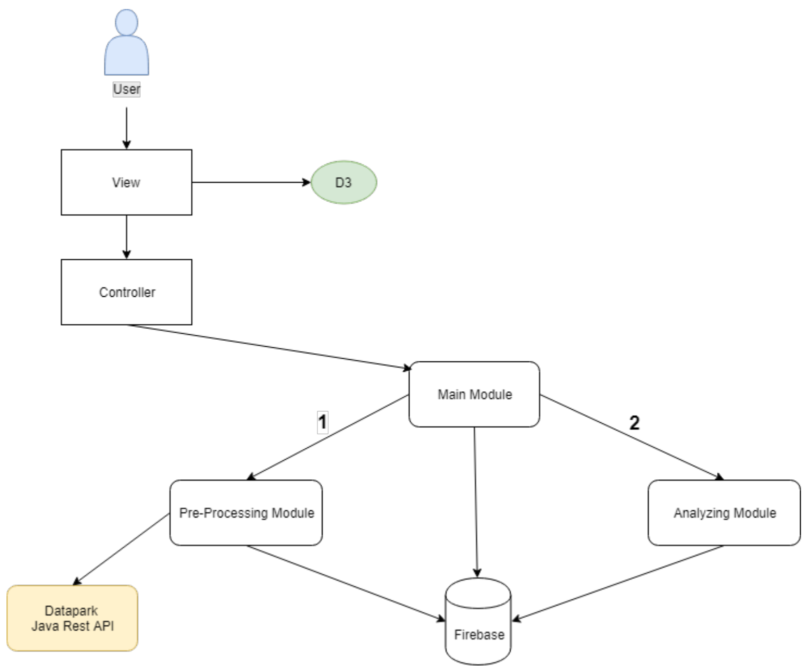

Figure 4.2: Consulting a report diagram

or create new ones from scratch. FileSaver[7], a j Javascript library, gives the opportunity to save files on the client-side from blobs. In the platform context is used to save PNG images from charts. An example of the interactions between the different modules could be the process of consulting a report for the first time, as shown in 4.2.

4.1.2 Data Model

Data Model gives an overview of the database organization. We have chosen a non-SQL database, Firebase[8], for its flexibility and capability of customizing. Also, it has an easy integration with different languages and platforms.

The particularity of this type of database is that each different type of data can have different attributes, and there are no pre-defined restrictions when saving data. Firebase has also other services, that we are using, like storage for files and user authentication.

Figure 4.3 shows the different Firebase structures we have created. Further detail for each one will be provided in the respective section.

Patient

The ”Patient” entity is shared between this project and others in the lab. In this description, I will only describe the relevant part of the attributes that I use on my thesis.

Each patient has a limit information saved, only the indispensable for analysis. Date of birth, height, weight, name is the basic information saved.

[7]https://github.com/eligrey/FileSaver.js/
[8]https://firebase.google.com/

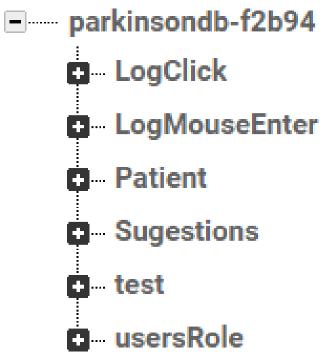

Figure 4.3: Overview of all Firebase structures

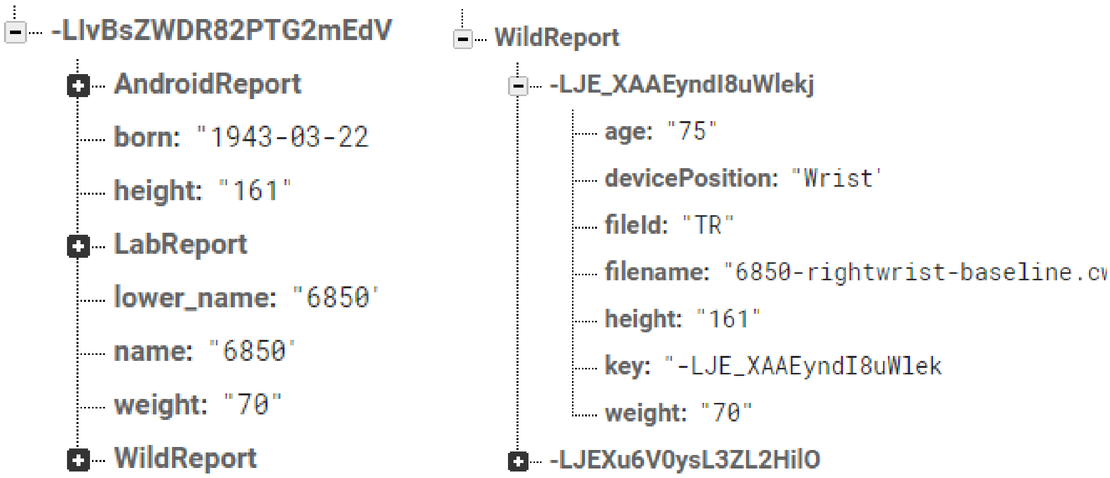

Figure 4.4: Patient Firebase structure

Each file upload will be associated to a patient and saved in a WildReport attribute. Entries in WildReport, as shown in 4.4, will also have age (calculated automatically from the date of birth), height and weight (if there is any change on patient's values). It is relevant to know this information at the moment the file was saved, because, for accuracy, the algorithms need to use the correct health data. Filename, devicePosition, and fileId (a file friendly name for user searching purposes) are the remaining attributes.

Users' Role

We use the "usersRole" entity to fill a limitation in saving users data. Firebase authentication saves the log in details (it depends of the mechanism chosen for authentication), in our case the email and the encrypted password, together with some pre-defined metadata, e.g.: a Boolean for already validated accounts. However, we needed to add extra fields to the user data. For that purpose, the solution we adopted was to create a new entity. We wanted to save role of each user, to differentiate its privileges. So, the "usersRole"

Figure 4.5: UsersRole Firebase structure

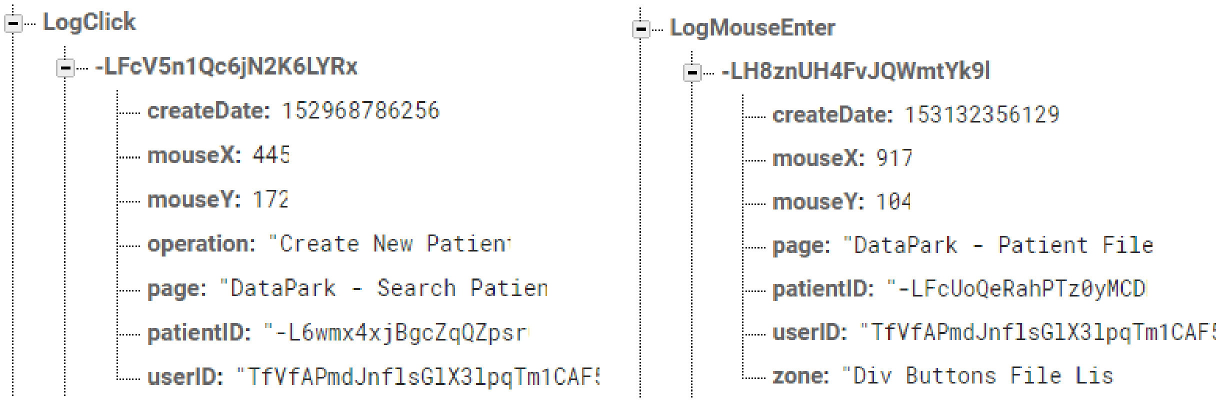

Figure 4.6: LogClick and LogMouseEnter Firebase structure

entity only have one field, a Boolean called ”isAdmin”. When a new user is created two things happen: a new row is added to the authentication table; a new entry is added to ”usersRole” entity (shown in figure 4.5. By default, a new user is created with minimum privileges.

Suggestions and Logs

For tracking back all the users’ usage of DataPark a series of logging mechanism were applied and saved in two data structures with similar data recorded.

The ”LogClick” entity have a field for saving what operation in the system was associated with. The ”LogMouseEnter” allows understanding in what areas the user navigated by saving when a different zone was entered. Both entities have common fields, as shown in figure 4.6, such as ”createDate”; ”mouseX” and ”mouseY”, for saving where on the screen the user clicked; ”page”, to know in which page the user was; ”patientID”; ”userID”. All this logging allows to know more information about DataPark usage.

A suggestion functionality was implemented to allow users to send new ways of improving the web app. The ”Suggestions” entity gives the information needed to know

Figure 4.7: Suggestions Firebase structure

when a user sends the suggestion and all the environment associated with it. It have as fields (like shown in 4.7): ”createDate”; ”page”; ”patientID”; ”userID”; ”suggestion”.

Logging and suggestions were created mostly for assessment purposes, and was relevant to collect subjective data in the evaluations (Chapter five).

4.2 System Implementation

There is a lot of work happening in the background with the support of technology. In this section I will explain what technologies I chose and why; how was the deployment process; what is needed to access data; and what is the purpose of the logging mechanism.

4.2.1 Used Technologies

Before starting to implement there was the need to choose what tools, programming languages, and third-party services to be used. One deciding factor here was the degree of knowledge of the technologies or what was the time needed to learn them. Other factors were the suitability of the tool chosen, depending on what we want for each specific case; the costs associated, whenever possible we opted for free tools; compatibility between different libraries; and the available documentation.

Back End

In the back end, the major decision was the programming language, the choice fell to Python[9] because of its scientific libraries. Django[10] is a free, open-source python framework that allow an easy build for web applications. The version used was 1.11. There is

[9]https://www.python.org/
[10]https://www.djangoproject.com/

a recent version (Django 2) but at the start of the project, the most recent was the chosen one. SciPy[11], a python, scientific library had a relevant role in the analysis of the data. Firebase Admin API[12] for python was used to access database and storage. Pandas[13], a python library, was used for reading and writing on CSV files.

The Pre-Processing Module (PPM), that is accessed by a Java Rest API, was created for processing the binary files. When a file is accessed by the first time, for any user, Main Module forwards a request to PPM. In PPM, a CWA file is received as input and after processing it produces a CSV file as output. The procedure consists in reading the binary file and extracting the information needed. Such as, timestamp and the axis values. After that, data is grouped in epoch, according to the request period (expressed in seconds). The final output has the initial timestamp of the epoch, mean values and standard deviations for each axis, combined standard deviation of the three axis, and mean vector magnitude calculated from the three axes. For accessing the files, it was used the Firebase[14] library for Java together with the Google Cloud Storage library[15].

Front End

There are a lot of technologies available for front-end developing. We decided for the ones that suits most with our needs. HTML5 is used for defining the page content, CSS to define page layout, Javascript[16] for providing a more dynamic view of the pages. Bootstrap[17] has a key role to help designing the pages.

The Javascript libraries were a crucial tool when developing. D3[18] was used for creating the distinct types of charts. Jquery[19] was used to manipulate HTML elements. Filesaver.js[20] allows to save blobs in image format. Firebase[21] was used to manage user session with a dedicated library for Javascript.

To manage user's session and the patient selected we used the browser cache. In Users' session we used the "localStorage" that stores data without any expiration date, allowing the session to remain always active. It will only be removed when user ends session or clears the cache. In patient currently selected we opted by "sessionStorage", that will only remain valid until the tab where was created is still alive. This allow users to have multiple windows with different patients in the same browser, per example it can

[11] https://www.scipy.org/
[12] https://firebase.google.com/docs/admin/setup
[13] https://pandas.pydata.org/
[14] https://firebase.google.com/docs/storage/admin/start
[15] http://googlecloudplatform.github.io/google-cloud-java/google-cloud-clients/apidocs/com/google/cloud/storage/Bucket.html
[16] https://www.javascript.com/
[17] http://getbootstrap.com/
[18] https://d3js.org/
[19] https://jquery.com/
[20] https://github.com/eligrey/FileSaver.js/
[21] https://firebase.google.com/docs/auth/web/start

be used for comparing patients' data.

Database

We choose Firebase[22] as our database, because gives more flexibility in how to manage data. Per example, each entity can have its own attributes, despite it belong to the same type of data. We used three of the many features Firebase offers: Database, Storage and Authentication. Firebase Real-time Database allows saving data in a NoSQL database with a JSON format. It is composed by entities that can have attributes (that can also be other entities). Firebase Storage is used to save files (binary CWA and CSV) in the cloud. Firebase Authentication gives an API for Javascript to control user session and access to application. It is also used for storing the user credentials for log in. In some languages (java per example), to access the Storage API it is needed to use Google Cloud Storage API[23], because it is the way Google organizes its API's accesses.

Deployment

To allow real users to use DataPark in their own environment it was needed to deploy it to a server to make it available. That was a novelty for me because it was the first time, I developed a program to be used outside a control environment. So, some barriers appeared at the beginning e.g., what was the best way and tools to deploy the web app. Of all the possible solutions, AppEngine[24] from Google was the chosen one because it offers the easiest integration and a free-quota on initial usage. It supports Django deployment using Ngnix[25] and Gunicorn[26], as webservers.

It was a good challenge to understand how to work it that but, in the end, I managed to overcome it and deploy the web app with success.

4.2.2 Background Work-flow

DataPark has tasks performed in the background that are relevant to be mentioned. I will explain the users' management process, the patients' management process, how to access data, and how the logging mechanism works.

Users' Management

The users' management (figure 4.8 was made using Firebase authentication that offers a set of functionalities to maintain a session using Javascript. This facilitates the process of registering, login and maintaining users active when navigating.

[22]https://firebase.google.com/
[23]https://cloud.google.com/storage/
[24]https://cloud.google.com/appengine/docs/
[25]https://www.nginx.com/
[26]https://gunicorn.org/

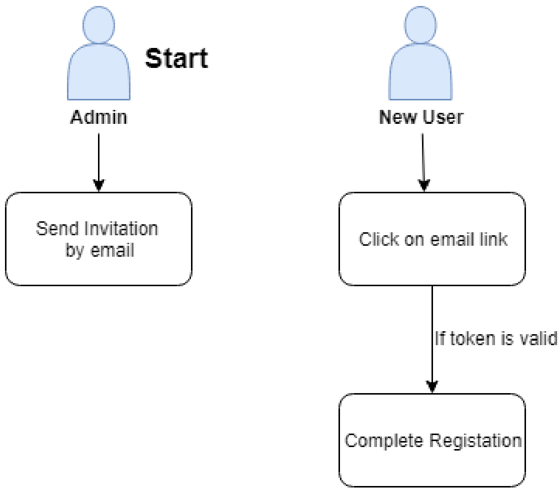

Figure 4.8: Users management work-flow

The process of registering, for the purpose of validating the prototype, is only performed by invitation by a user admin. This special user can send invites for the new user's email, that had one-week validation period, until it expires. When the email is sent, a token is generated; when the new user clicks at the link on the e-mail, that token is used to validate if everything is according to the rules (email is correct, and the token is valid). Finally, the new user should choose a password according to the security rules (It must have at least eight characters) and then be able to use his account. The log in is performed with the email and password mechanism. When valid, it creates a session for that user that is valid until log out is clicked.

Patients' Management

The Patients' Management (figure 4.9) involves creating, editing and deleting patients. It also consists on saving the current selected patient, for that we resorted to the session storage mechanism of Javascript.

To create a patient it is only needed to fill a form with the profile data If needed it is possible to edit patient profile information and also delete the patient, the files we not be deleted (for prototype version only) to avoid data lost.

According to the procedure defined, the best option for navigating through patients' data is to select a current patient. That selection allows to navigate to all the data available for that patient. For prototyping purposes, we created a test user, that will be selected by default, giving the chance to use random files to visualize data.

Data Access

The Data Access (figure 4.10) is related with the process of uploading and visualizing data. In the next steps I describe how this works, assuming we have already a created

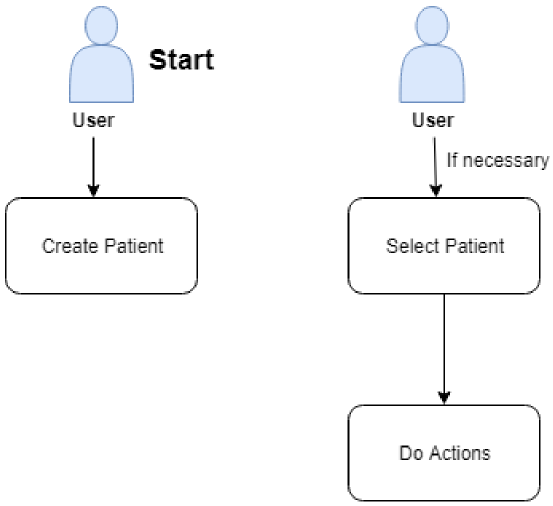

Figure 4.9: Patients management work-flow

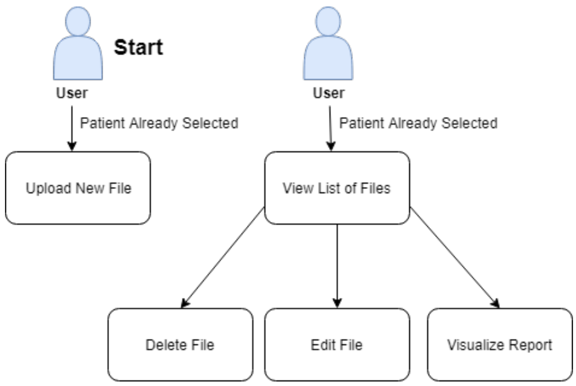

Figure 4.10: Data access work-flow

and/or selected patient.

First step is to upload a new file on the system. After that, the desired file must be selected for analysis. In the background, file is saved on storage, a new file with summary data is than created and all the data to build a report is generated.

Logging

To understand DataPark usage, users' difficulties and what functionalities are most used a logging mechanism were implement. It consists in saving user clicks on actions and in which section he/she navigates. For an easy way of receiving users' opinions about aspects to improve a feedback mechanism was created that allows users to send suggestions that allow us, together with logging, to watch what areas should be improved.

4.3 Assessing Activity Data

The input of DataPark is a binary file on CWA format. The first part of processing consists in converting that data to a more workable one, extracting x,y,z and timestamp of the sensor. For that purpose, the binary data is extracted from the CWA file and grouped in epoch. The API developed allows to define which epoch period are going to be used (only in seconds). We opted for using five seconds because it can capture the necessary time for analysis. When producing the output file, already in five seconds window epoch, the vector magnitude, the combined standard deviation and the standard deviation for each axis is calculated.

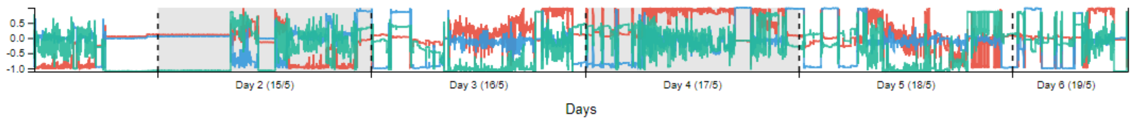

Figure 4.11: Raw chart example

Figure 4.11 is an example of a seven day chart with the x,y,z synchronized with the timestamp to show the variation of the acceleration in the different axis. No processing was performed; this step only converts the information on binary file calling the Java Rest API implemented and outputs a CSV file to Firebase storage, for future access.

Other algorithms could be part of the platform, but for the time of this thesis only the below ones are fully implemented, some of the others are in early or intermediary stages of development, for example, free-living gait analysis.

4.3.1 Energy Expenditure

In the pre-processing module, we also calculate the signal vector magnitude algorithm that together with patient's weight gives the energy spent. First the formula $vm = \sqrt{x^2 + y^2 + z^2}$ is used to get vector magnitude by combining the acceleration in the three axes. When energy expenditure is requested the formula $EE = 1.05 \times METs \times Duration \times Weight$ where Weight(kg) corresponds to people weight and Duration is the time interval (in hours). METs is calculated from $METs = 0.96 \times Speed - 0.13$ where speed is the velocity $v = at$, a is the acceleration (Vector Magnitude) and t the period of time spent in acceleration (epoch period). Figure 4.12 shows an example of the energy expenditure in a period of seven days [3].

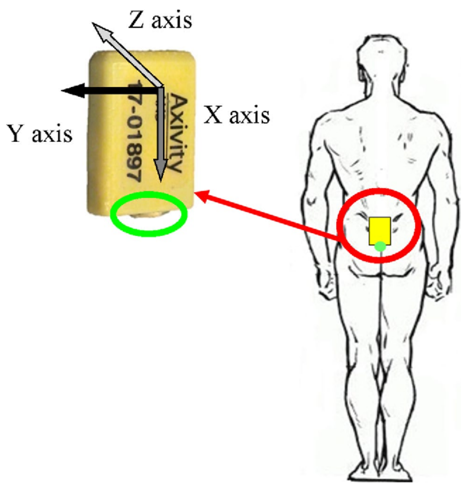

Figure 4.13: A representation of the axis and its respective correspondence. X is v, Y is ml and Z is ap

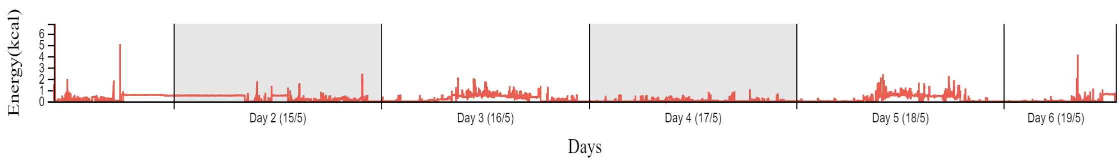

Figure 4.12: Energy chart example

4.3.2 Position and Transitions

Physical activity (PA) is an important feature for analysis, because it shows how was patients' day. For obtaining PA it is needed to know first what body positions and transitions along the day were. The algorithm consists in estimate which position people were (sitting, standing, lying, walking or other). From the three axis values, its standard deviation and the combined standard deviation, the following formulas [21] [18] are applied:

- Lying $ml >= lyingThreshold$ or $ap >= lyingThreshold$
- Sitting $ap < 0$ and $vAnt > v$
- Standing $ap < 0$ and $vAnt <= v$
- Walking $v >= thresholdVMin$ and $v <= thresholdVMax$ and $combStd >= thresholdStd$

Where ml is mediolateral axis, ap is anteroposterior axis, v is vertical axis, vAnt is the previous value of v (See figure 4.13 for further details). Each one of the thresholds values are also applied for its negative value. In the figure 4.14 is showed a possible chart obtained with the data analyzed from the sensors.

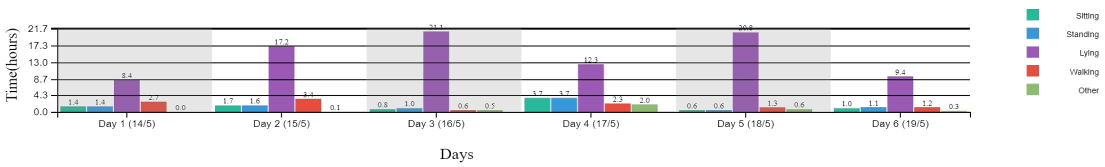

Figure 4.14: Position chart example

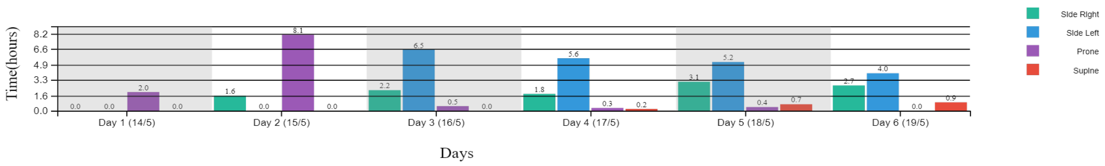

Figure 4.15: Sleep chart example

4.3.3 Lying

Based on the sensor location (trunk), and knowledge about sensor placement, the sleep analysis consists in understanding the different possible body transitions. The vertical axis is used only to detect if the subject is in lying mode. There are four possible lying positions Turn Left (ml [27] positive), Turn Right (ml negative), Prone (ap [28] negative), Supine (ap positive). These will depend on the chosen axis configuration, here x was vertical and stand up means negative values. Finally, all the possible values for positions must be above a pre-defined threshold that guaranteed subject is lying. For defining sleep periods, it must be considered a prolonged period of lying down without major transactions between positions. A major transition is change to another position for an extended period of time. In the figure 4.15 is showed a possible chart obtained with the transitions during sleep.

4.4 Interacting with data

DataPark was designed to work in any operating system or browser. I will present some of the more relevant user interfaces of the platform, that tries to show most of the system interactions. Windows operating system and Google Chrome are used in the figures below.

User Registration

The registration process involves admin privileges. It consists in three steps: sending an invitation (shown on figure 4.16, new user email validation and complete registration process (figure 4.17. For prototyping purposes, there is already a predefined admin user

[27] mediolateral
[28] anteroposterior

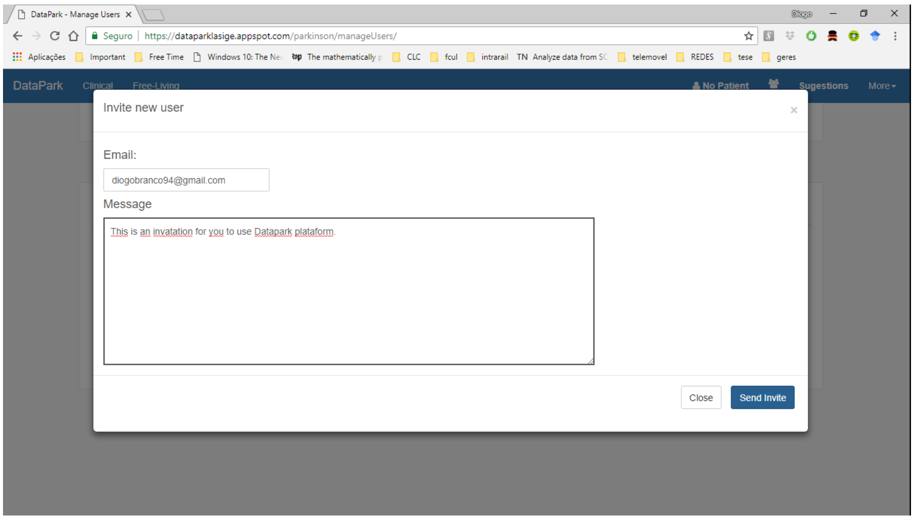

Figure 4.16: Send new invitation page

for each medical center that has access to send new user invitations. So, the first step is to send an invite to new users by filling the form with a message to be sent by email. Validations are performed to guarantee that both fields are filled correctly. In the email, the new user should click on the link that will redirect him/her to a page that verifies if the registration link is still valid and asks for the password to be defined. For security purposes each password should have at least eight characters and must be filled twice for checking, all the validations are performed without the need to reload the page.

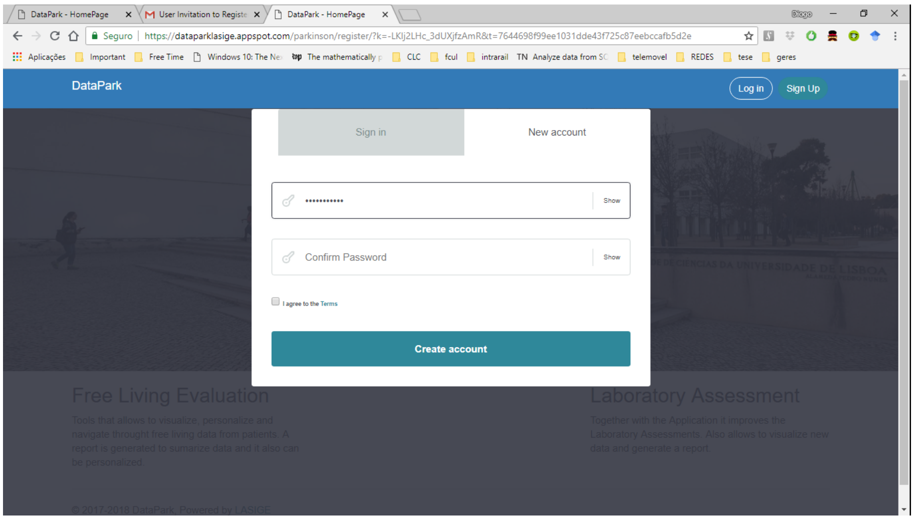

Figure 4.17: Complete registration page

So finally, the user is able to the use his account after log in into the system. He will be redirected to the patients' list page.

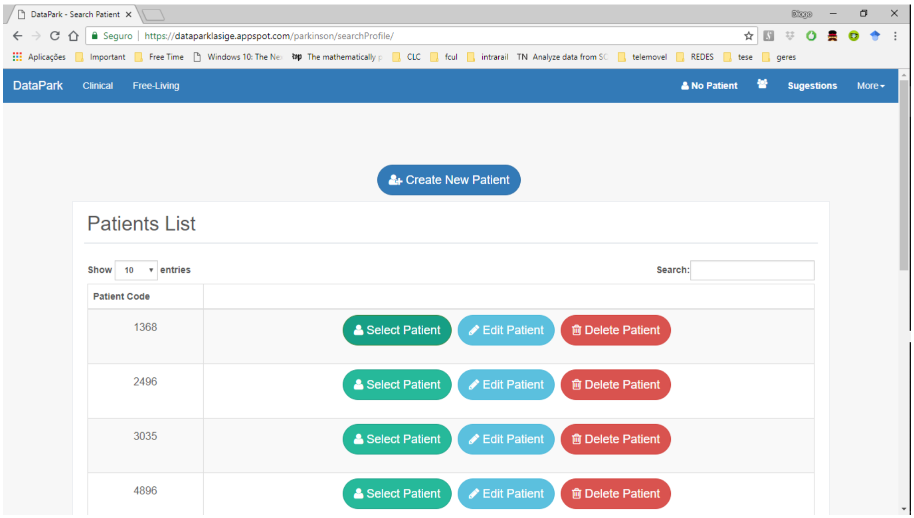

Figure 4.19: Patients' list page

Patient Registration

To register a patient, the user, a clinician, only needs to fill a form with basic profile information: age, height, weight and subject code (figure 4.18. Other information can be added afterwards.

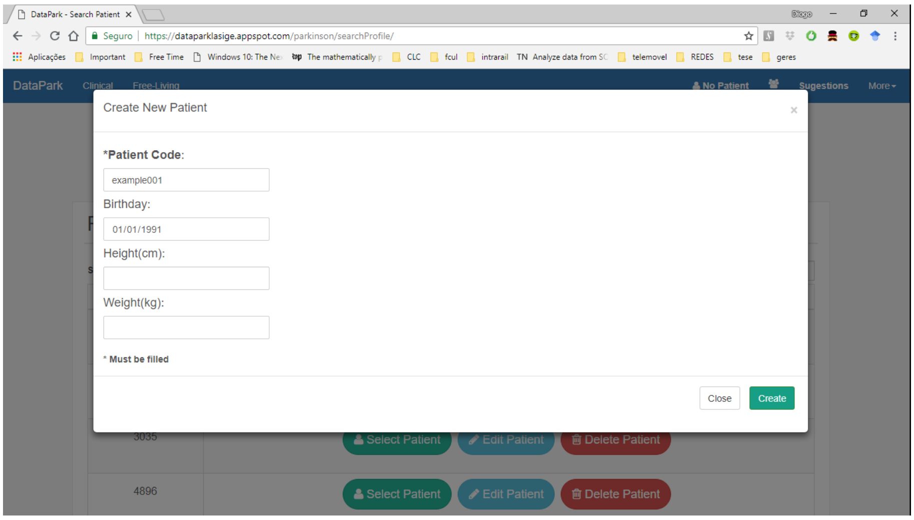

Figure 4.18: Create new patient

Upload New Files

The first step to upload a new data file is to select the patient, like in figure 4.19. The patient can be selected from a patient list (search is enabled). For prototyping purposes, there is a "test patient" where random files can be added for analysis. Next step is to select the free-living page and click on the Upload button. That will redirect to a new page that consists on filling a form, such as the one on figure 4.20, with the file to be uploaded

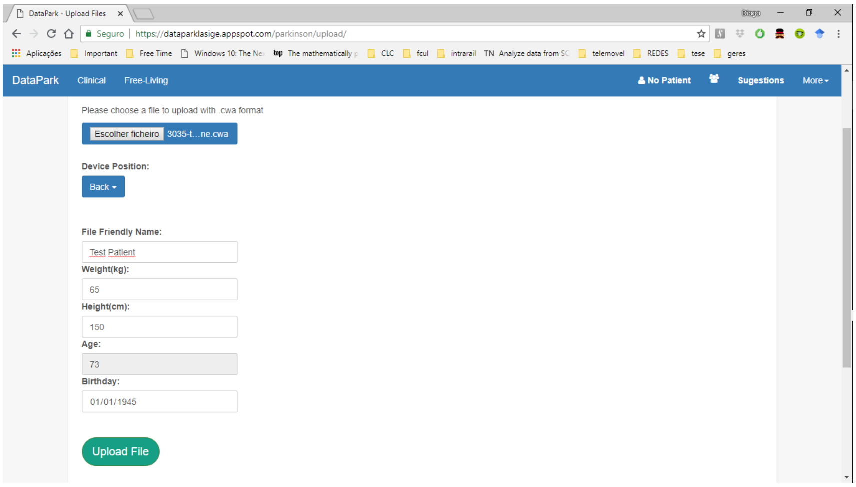

Figure 4.20: Upload new file page

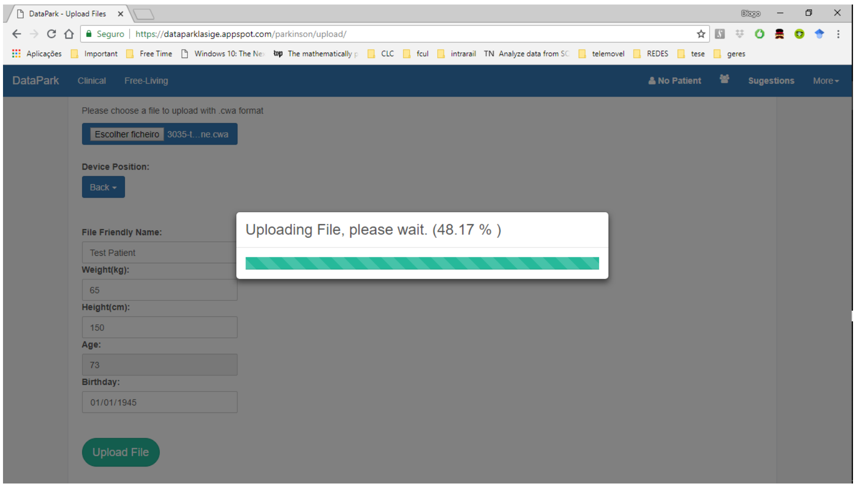

Figure 4.21: Visual feedback while uploading new file

followed by extra information (birthday date , if not yet filled on patients' profile, weight and height, if there is any changes on them), also the user can choose a friendly name. All the fields must be filled, and a final check is done after submitting the form. Because the data consists of files of about two hundred megabytes, for a period of seven days, there is a upload progress indicator, shown on figure 4.21, that gives feedback on the percentage of the file that is already on the server. After the upload is correctly ended, the user will be redirected to the list of free-living files.

Visualize a Report

For being able to visualize the report a patient must be selected, but only if this is a different one. DataPark saves a current patient, that only changes when the user selects a different one. The next step is to go to the free-living file list (figure 4.22), and select the one wanted for visualizing the report. The user can also edit all the information previously

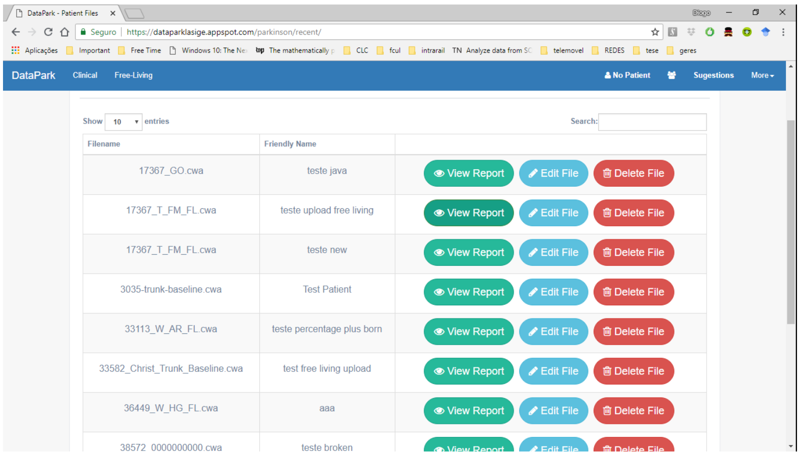

Figure 4.22: Files list page

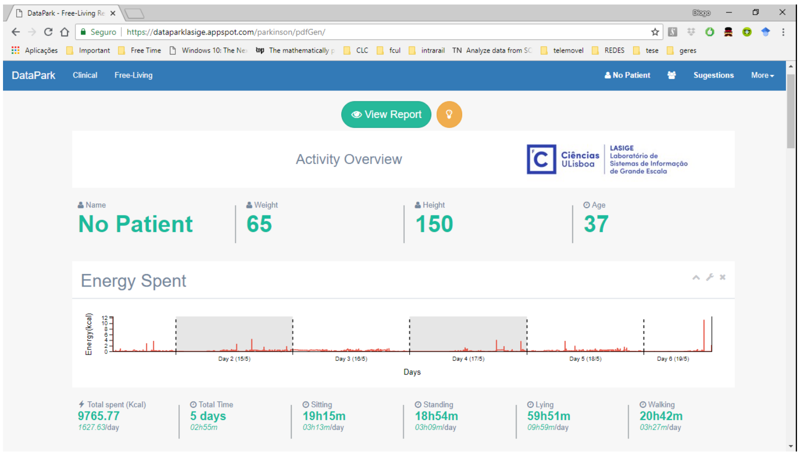

Figure 4.23: Report visualization page

inserted and can inclusively delete it. Now, after all the data is loaded a report (figure 4.23) with a set of default charts and other textual information, will be presented to the user. There are several ways to interact with the report: applying filters, personalizing and creating custom reports, downloading charts as images, and visualizing and downloading the report in a PDF format.

Users' Management

There are two types of users: normal and admin The unique difference between them is that admin has access to the list of registered users (figure 4.24) and can send invites to new users (figure 4.25). To manage users, it is needed an admin account.

The registered users table allow consulting who are using the platform. It also has the option of deleting users that are not using it anymore. There are no major damages when deleting users because there no association between them and other resources.

Outside the prototype phase, each medical center should have at least one admin that

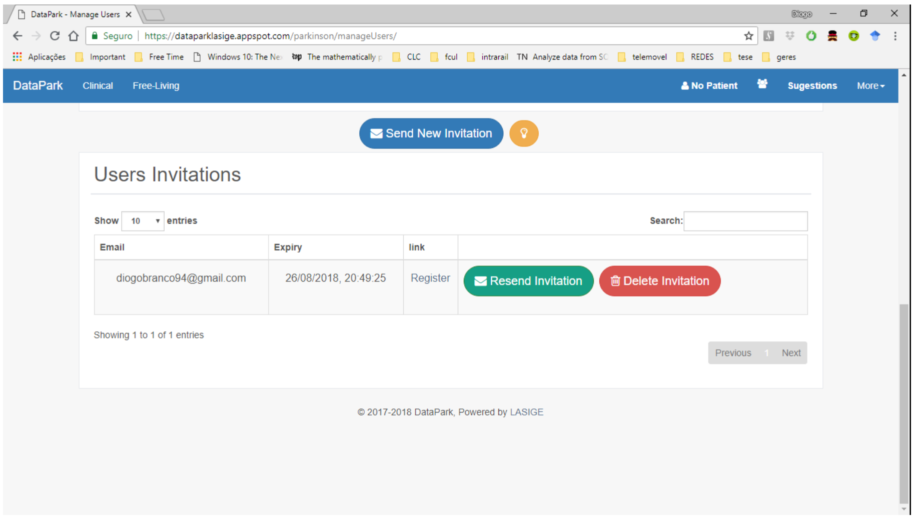

Figure 4.25: List of current invitations

has access to his intuitions' users; it must also keep track off more detailed information about each user, like which patients and files they interact with. It is important not only for knowing who did what, but also to keep track of all the interactions between patients and clinicians.

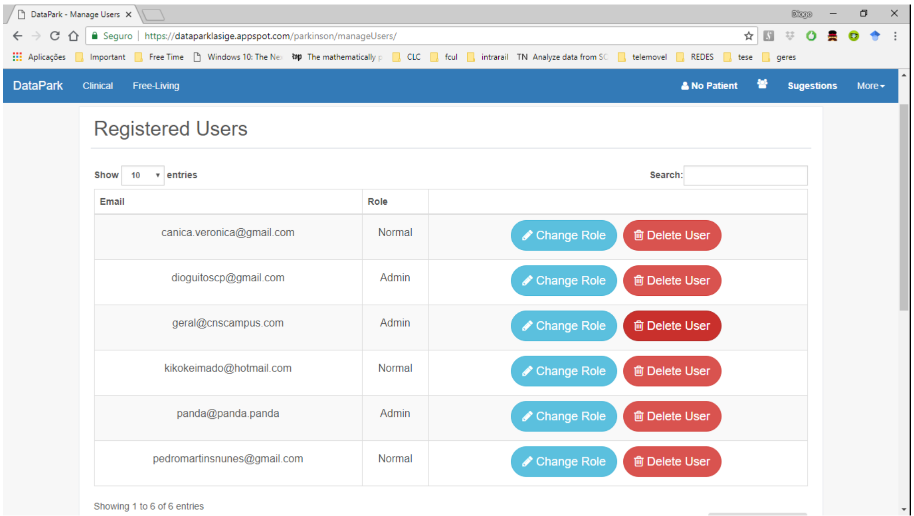

Figure 4.24: List of current users

Like it was mentioned in the "register a user" section, the admin can also send invites to new users. If a token expires or the new user loses or does not receive the email, it can be sent again.

Send a suggestion

This project is exploring a new paradigm in healthcare. As such, it is important to collect data about its usages so that it can be better designed to fit the users' needs. To collect information from users, the prototype includes a way for users to send suggestions (figure 4.26) about the several interface elements, particularly the ones with data. Is an interaction that makes a lot of sense in the prototyping phase because it allows to receive fast feedback from users. In this phase could also make sense but have to be an automatic mechanism that detect suggestion and correct some of them in an autonomous way.

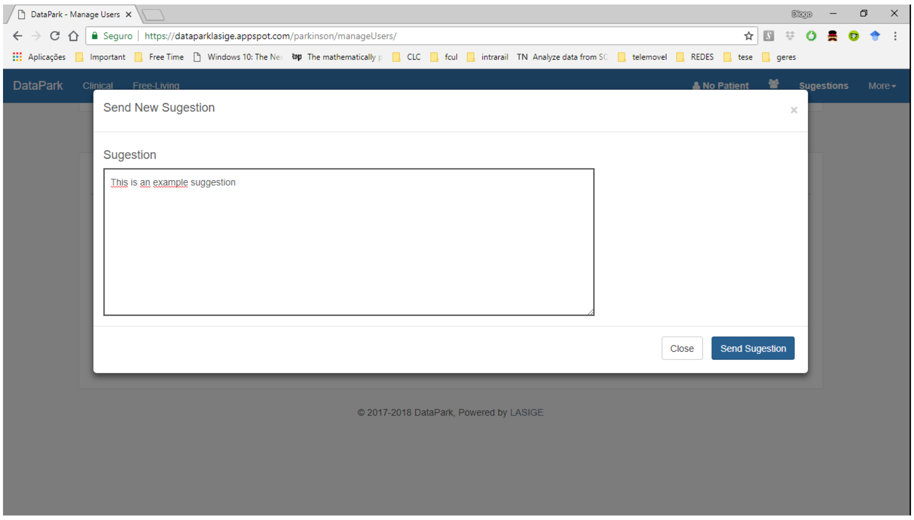

Figure 4.26: Send new suggestion

4.5 Reporting The Results

In the free-living analysis, there is a pre-generated report based on all the information collected that consists of different ways of showing energy, sleep and positions metrics. Regarding Energy we provide a summary analysis about how much energy was spent by day, a general overview; in each day grouping energy spent by levels of activity (sedentary, moderate or vigorous) and how much energy was spent in each day in the different periods (Morning, Afternoon, Night or Dawn). Position reports allow to understand how much time was spent in each position by day. Sleep gives an overall summary, positions changes during sleep (different position in sleep but still lying), positions changes that look like to be a wake-up and how much time was spent in each sleep position.

Building a default report template was an iterative process. We iterated on the design aspects, different ways of showing data, including other types of charts or ways of working the information contained therein. We were also concerned with readability as the reports are eventually relevant for patients also. As such, we took consideration on text color, size, chart colors and contrast, among others. These were discussed and iterated with the clinicians that co-designed the report with us. Finally, it was necessary to allow these reports to have a way of surviving outside the platform context, so the PDF generation was the best solution found. It is then possible to save an electronic PDF report, like the one on figure 4.27 but also to print it for archive or delivering to patients.

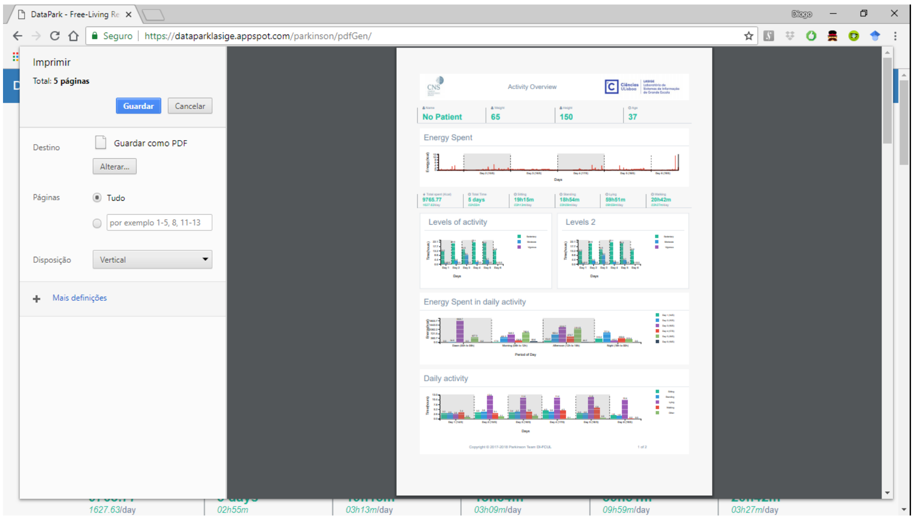

Figure 4.27: Save or visualization of the report in pdf

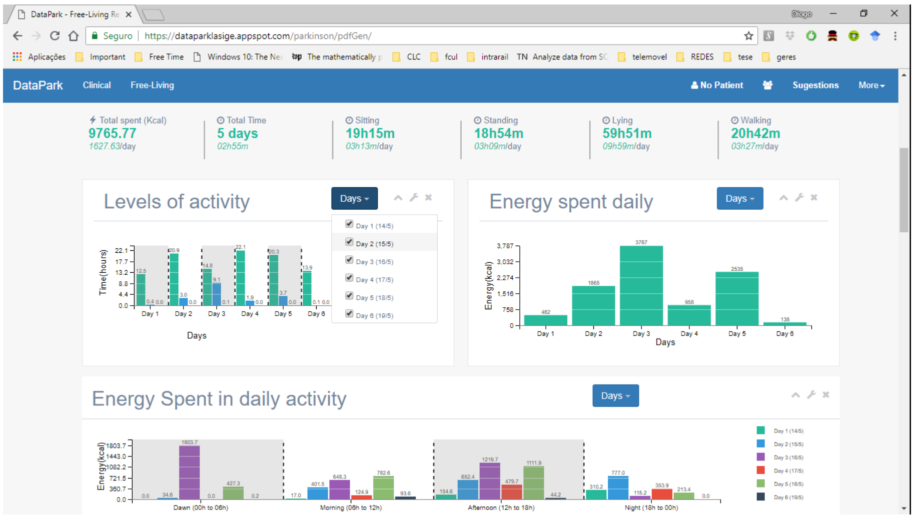

Figure 4.28: Apply a filter example

Customization of the report was an aspect to have in the consideration because it is important to generalize report building to adapt to all needs. First filtering the data (figure 4.28) to be shown in each chart, for example, the days present or the axis (on x,y,z raw data visualization). Clinicians may wish to adapt reports for a particular user or because of their own preferences. We accepted this requirement and looked to provide complete flexibility in creating a report.

I decided to develop a way for each user to create their own report with the help of template charts (figure 4.29). Clinicians can choose what charts should be present and in which position of the report, also it is possible to have the same chart more the one time to show distinct aspects, for examples on different days. In the context of this thesis this tool is not fully finished, but all the previous features mentioned about it are possible to use for each user. But I want to have an even more generic tool that allows not only to choose

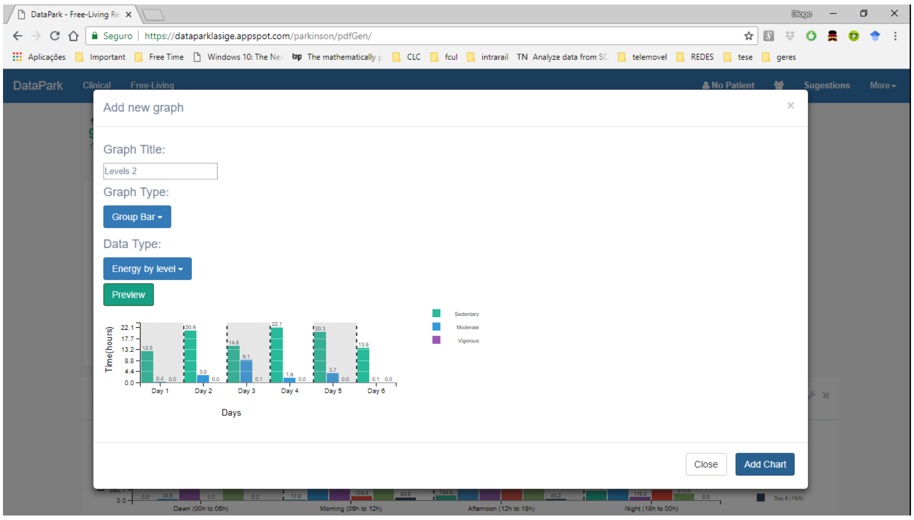

Figure 4.29: Example of how to build a personalized report

from a set of charts but also allows to insert and build new ones on the moment, that way an automatic report tool is fully integrated inside the platform and allows to generate any type of chart or information report.

Chapter 5

Results

The collaboration with CNS enabled us to put our platform to the test in a real environment. All the process was iterative. I started by using data from patients to produce summary data for each category (sleep, energy expenditure, physical activity). The analyzed data are available in the platform as a set of charts or PDF report. The reports can be used for clinicians' analysis and/or to show and discuss with patients. We evaluate the impact reports have for clinicians, how the data helped to understand what happened with patients, the global report design, and each chart design individually.

Based on what I learned from previous tests and conversations with clinicians, I have improved the report design and each chart individuality. In the report global vision, the main features improved were: the display of charts and metrics, and what kind of data is presented. Each chart was adjusted in color scheme and presentation (axis, lines, labels); for each data different charts were tested, and I selected the most suitable for each case.

Our first deployment of DataPark was during a rehabilitation program at CNS. Where seven young people with Parkinson's disease used the sensors. At the end, a report was available for clinicians to give and discuss them with patients. The results obtained were more related to the improved report and we find out that reports were not discussed in detail with patients. However, in posterior conversations with clinicians, we understand that patients liked the kind of measures we can give them because it can show them new perspectives their day to day.

We also took part in the first CNS congress for Parkinson's disease. We presented two topics. The first was an explanation of our research with inertial sensors and subjective data in free-living environment. We explained our approach and how we think we can contribute with technology for improving the knowledge about patients. The second presentation was all about clinical evaluation and how inertial sensors can be part of this environment. The feedback from participants was excellent. Participants show a lot of interest in the research we are doing.

We participated in *Encontro Ciências 2018* with one project presentation and a demonstration session, named using inertial sensors in the onsite and free-living assessment of

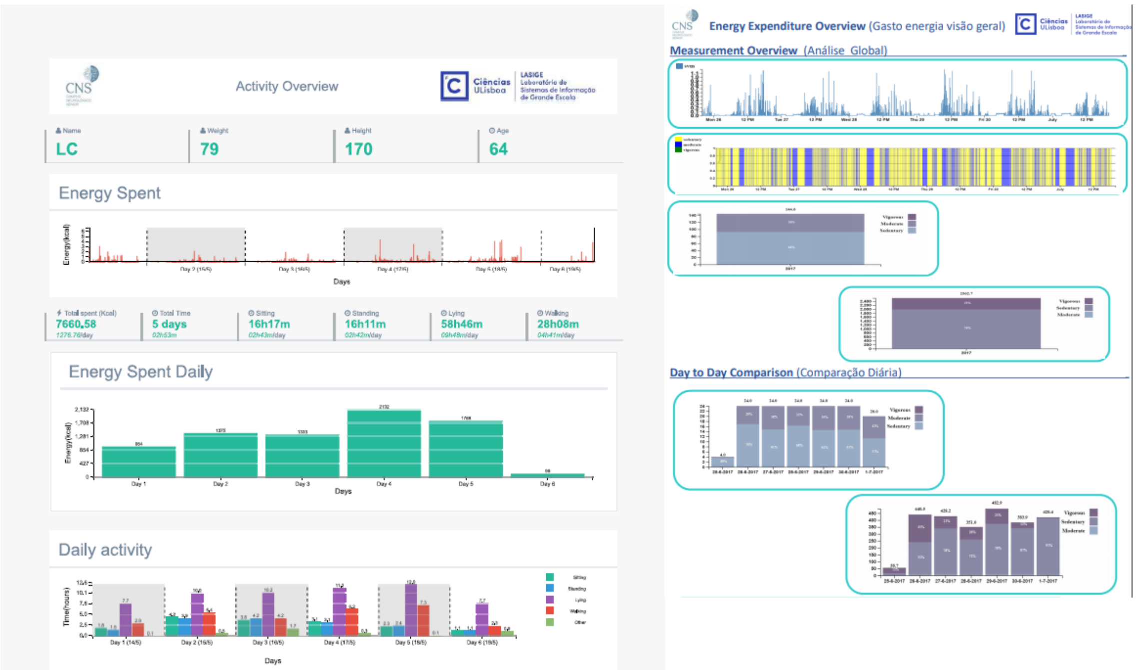

Figure 5.1: Example of the old report design (right) and the final report design (right

Parkinson's. The project presentation consisted in showing an overview of our research about Parkinson's. We explained the objective and subjective data collecting procedure and how all is integrated in the platform. The demonstration consisted in a showcase of DataPark, with the focus in reports. The feedback was excellent, and people showed interest in our research.

Finally, we performed two studies with concrete goals for obtaining validations about DataPark. The first was in a rehabilitation week at CNS. The second was a longitudinal study were clinicians used the platform freely for over two months.

5.1 One Week Study

This study was performed together with Campus Neurológico Sénior and its main goal was to validate the quality of the reports being generated. Despite some initial validations have been already performed, this study had the main purpose of understanding if clinicians considered DataPark useful. Other validations were related to approve a last version of the default report that should take in account the expectations of both patients and clinicians.

5.1.1 Research Goals

The main goals were to:

- Understand what the usage are given by clinicians to the platform

- Understand the quality and limitations of the output data analysis

5.1.2 Participants

Three therapists used the platform and worked directly with the platform recruiting a total of six patients with Parkinson's disease. To be able to participate in the study, patients had to have Parkinson's, being predisposed to use a sensor for a period of seven days and agree with the protocol defined.

5.1.3 Procedure

First, we met the therapists to define the protocol to be used in the study. Explain how they could interact with DataPark and understand what their concerns and expectations about the platform were.

The study was performed in the Campus Neurolórico Sénior (CNS) Summer Campus that has a duration of seven days. At day one, after initial clinical evaluation, patients started using the sensors. During that period, they did their normal daily tasks and the only request was not to remove the sensor. In day seven, therapists remove the sensor and use the platform to visualize a report of the week. After that, they deliver and discuss that report with patients.

5.1.4 Data Analysis

Initial informal interviews were performed to all the therapists to understand what their concerns and difficulties about the usage of DataPark were. Final informal interviews allowed to perceive how the platform influence both negative and positive the normal workflow of dealing with the patient.

During the initial and final patients' evaluation by clinicians we observed all that happen. We throw notes of clinician' feedback and our own interpretation of DataPark usage. It was allowed to record videos of the evaluations and to assist the questionnaire responses. That gave us the opportunity to a posterior analysis of algorithms being applied versus video recording.

5.1.5 Findings

Overview

Clinicians only used few of the functionalities available in DataPark. Only one of them handled creating accounts and work directly with the web version of DataPark. The others only used the mobile application for lab assessments.

The sensor location and orientation were a detected problem in clinicians that do not have previous experience in working with this kind of technology.

Patients have already used inertial sensor in preliminary validations, so it was a normal procedure for them. Despite the procedure does not take much time clinicians mentioned that it should be a way of only put the sensors one time and remove at the end. Now it needs to put and remove, for extracting data, between lab assessments and free-living usage.

Reports were only given to patients after we left. However, we could get the feedback from clinicians' perspective and they also told us what patients feel about it. Clinicians expect data gives what they are thinking, per example about levels of physical activity. It was necessary to explain what is been showed so they could understand what that was the data output. Patients like to have an overview of how their week was. Examples of what they like the most are energy expenditure (expressed in kcal) and sleep analysis.

Benefits

Both Clinicians and patients benefit from having a summarized report of the seven days period. Clinicians had objective data for substantiate in the discussion with patients. Patients have access to an overview of energy expenditure, physical activity, and sleep analysis for the week. This completes the normal procedure of initial and final evaluation by giving also a global overview of patients' week.

Limitations

Patients have a little discomfort in wearing the waist sensor for an extended period of time. This study was performed in a free-living, however patients stayed at the clinical for the campus, so they were outside their normal environment.

Patient know they are being evaluated, some of their behavior could not be the same if they are at their home without being aware that they are being evaluated. The functionality of clinicians create personalized reports was not used. Their limit time for each patient leads to only using the template report.

5.2 Longitudinal Study

This study was performed together with Campus Neurológico Sénior and its main purpose was to validate DataPark as a tool to help clinicians to better understand what happens with patients outside the clinical context. Most of the functionality was tested for the first time on the study, despite some previous presentations, clinicians have not interacted with DataPark.

5.2.1 Research Goals

- Understand benefits and limitations
- Understand how it influences clinical practice

5.2.2 Participants

Therapists worked directly with the platform and recruited a total of sixteen patients with Parkinson's disease. For being able to participate in the study patients must have been diagnosed with Parkinson, being predisposed to use a sensor for more than one day and agree with the protocol defined.

5.2.3 Procedure

An initial meeting occurred with the therapists to define the protocol to be used and explain all the main functionalities DataPark supports. This study has been performed both on CNS Torres Vedras and CNS Lisboa. When patients went to an appointment, they were requested to use the sensor three days before it and three days after it, so an analysis could be done by clinicians comparing the two periods. After they returned, a report could be generated based on the sensor data. That report should be delivered to the patients.

5.2.4 Data Analysis

There was intermediary feedback received from one of the therapists that reported minor improvements and suggestions. At the end of the study, we performed an online survey with clinicians that were directly involved with DataPark.

The survey was divided in six categories: Patients, Mobile Application, Web Application, Reports of Clinical Evaluation, Reports of Functional Evaluation and Functionalities. For the scope of this thesis the reports of clinical evaluation and mobile application categories will not be covered.

Patients category give an overview of how the sensors influence them and the way clinicians have to interact with them. Web Application was for understand what the benefits and limitations were of using the platform. Reports of functional evaluation as the purpose of characterizing the impact of the analysis in both patients and clinicians. Functionalities was for perceive what were the most key features in clinicians' opinion.

5.2.5 Results

We obtained a total of three responses from clinicians. Here, we report the results of the study and include the therapists' subjective opinion where it makes sense.

Patients

A total of sixteen patients were evaluated in free-living using inertial sensors and our platform. Clinicians reported no changes in taking care of patients by using sensors. It shows that inertial sensors do not influence the normal procedure. However, one of the therapists said:

"Maybe it can make patients more anxious."

Web Application

We can conclude that the use of the web application does not influence the time to perform tasks. In the same way, there were no major difficulties on using the web application neither the initial time of learning was big. It was reported that:

> *"The upload process should be improved because there is not much feedback."*

> *"The reports should have a better version for printing purposes."*

> *"It could be more intuitive or have more captions to explain the charts and how it was calculated."*

In the suggestion box there was also feedback. An example is that:

> *"Should appear the reference values for the metrics that need that."*

Reports

The functional reports were of easy comprehension. All the data presented in the reports were important for clinicians and they considered that having this type of monitoring gives the opportunity for better understanding patients in a free-living context. However, none of the clinicians discussed the reports with patients. One improvement for data available in the report was suggest by a clinician:

> *"It would be important to analyze gait in a free-living context."*

Influence of functionalities

Clinicians pointed negative aspects of using sensors. They told that:

> *"The comparison of the data in different periods, if there was a regression in the results, it could lead to patients' demotivation."*

More from a clinical perspective a clinician said:

> *"If getting the data and understand it is a very complex process, it would not work and could harm the evaluation."*

They also pointed positive aspects:

> *"Allow to have a more objective perception of the results of each stage of the evaluation."*

> *"Greater accuracy in patient assessment and monitoring."*

> *"Possibility to have a more real perspective on the functional state of the patient in their environment."*

Regarding to DataPark functionalities clinicians, reported they were all of great utility, mainly the related to obtaining data from patients.

5.3 Discussion

DataPark appears after this initial stage together with intermediary validations of major concepts, like what kind of what data should be available and how should it be presented. We designed the first sketches of the platform, with interactions and logic sequences between actions, and tested with clinicians.

The free-living report passed to a lot of iterative design together with a clinician. I proposed different prototype and show them. Next, I iterated through them until a final version ready for real-world testing. For that matter, the one-week study was used to validate the report design and data relevance for both clinicians and patient. For clinicians it was a good improve to have objective data that gives a picture of patients' daily life. Although this may open a door for discussion between clinicians and patients, studies showed this did not happen, at least in a formal way. Patients had access to a paper copy of the report and it was an incentive for them being able to know their fluctuations throughout the day. In my opinion and based on the feedback received, reports must be easy to read for patients. This can be done having different version for clinicians and patients, because their knowledge and expectations are different. Patients need simple things that can be easy to understand, so more complex analysis it is not relevant for them. By the other side, clinicians need much more information that should be intuitive, but can have a more degree of complexity.

The final study had the purpose to understand the influence of DataPark in clinical practice. The platform was used continuously for evaluating patients in lab and free-living context. Although the survey did not have much responses, the feedback we received since the beginning show us that DataPark as the necessary potential for helping clinicians. We can affirm there is a gap to be filled in clinical evaluation where DataPark can take its role. The capability of having objective data that opens new perspectives of analysis it is a main advantage for clinicians. There is only the need to provide a tool that gives simple and fast interactions for obtaining data. That was something we try to achieve with DataPark, but there is the necessity of improving it.

Studies allowed us to noticed problems related to the sensor placing. Clinicians reported patients often have temporary psychological issues that take them to throw out the sensor. Sometimes, clinicians do not know where it was, and it is lost. Adding to it, having principally a waist sensor is something not natural for patients, however the wrist sensor has a higher acceptance rate.

The logging mechanism used in both studies give us a picture of what functionalities were more used. As expected, the ones related to data consultation had the higher rates of usage. Such as, report visualization and upload a file. By the other side, features like downloading charts as an image and create a customized report had low rates of usage.

DataPark started to be used for the study, but it will continuously be used by clinicians.

Chapter 6

Conclusion

DataPark is a platform build from three main pillars: free-living, laboratory and subjective. This thesis is only focused on the free-living part and was build based on the analysis of the related work, the defined requirements, and the discussion processes with clinicians. The main goal of DataPark is to help clinicians understand how patients' condition fluctuated during their day to day.

Despite there are already some tools that give some analysis on the data, the output produced is not user-centered and is an obstacle for clinicians to use it. Most tools use sensors and give information like energy and step count but the algorithms used are proprietary, so we cannot be sure what type of analysis is really being performed. In a clinical context is important to only used pre-validated devices and algorithms to be sure of the output being used. For this to have a real impact on decisions it must be guaranteed that data is trustful.

The principal functionality is the ability to convert a binary file format in pretty, personalized, interactive, and easily readable report. Reports can also be a subject of discussion on the interactions between patients and clinicians to give both objective goals that they can define with the focus being the improve of patients' daily life.

DataPark started to be used for the study, but it will continuously be used by clinicians. Their interest in having new ways of analysis gives more opportunity for us to explore. There is a huge set of resources that have a lot of research potential and it can be part of DataPark evolution. I see this platform as a tool with the necessary characteristics to make the difference in how clinicians gather more objective data from patients.

Here I try to summarize what was the work involved in the thesis dividing it into benefits, limitations, and future work.

6.1 Benefits

After the various interviews, talks and the studies, we can affirm that DataPark has a lot of perceived benefits for clinicians:

- More information about patients, especially outside a controlled environment;
- Obtain objective data that complements the subjective data and observations already happening;
- Create personalized reports that having in consideration different analysis need for each patient;
- Historical background of different reports allowing to understand evolution over time;
- Allows giving and discuss the report with patients by having a printed or digital version of it;

Despite no formal interviews were done with patients, we can infer that DataPark helps in improving patients' quality of life:

- More information can be obtained that helps understand how the daily patient's evolution was;
- Allow a new way of discussion between clinician and patient, helping patients to explain how they felt;
- Gives a printed version of the report to the patient that improves is motivation to try to get new goals;

6.2 Limitations

This thesis gave a first step towards data-driven Parkinson's disease assessment. Studies were only a preliminary validation of the approach. Nor all the benefits of DataPark could be validated alongside the study. I wish I had the time to validate even more with the focus on how reports can change the relationship between patients and clinicians. Mostly related to understand what is the real impact of reports for patients and understand how they should be improved to have more readable design if needed.

The time needed to generate a report could lead to a non-usage of the platform. Personalized reports should allow to be saved for later use. Our final study only had three responses, so a broader study in needed to infer if it influences (positive or negative) the clinical environment.

A major study for comparing the objective data obtained with the subjective information that clinicians already have. It will also be important to understand what are the correlations between these two of ways of getting data from patients activity outside a controlled environment.

6.3 Future Work

DataPark has reached a stable version that can be used, however, it has the potential for growth and allow to do much more:

- Start to use **sensor only on wrist**, because it will lead to more comfort and high rates of acceptances for patients. There is already research about it, but more validation is needed.
- **Improve the time** needed to generate a report, by applying optimization techniques.
- **Generalization of the report** creation, allow saving each personalized report in a template that could be used in other reports.
- Add more filters and **construct a generic filter system**. Each chart as his own filters but sometimes it shares the filters type with others, build a tool the gives the user the opportunity to apply a set of template filters already created or add new ones.
- Modify the way reports are personalized by allowing the user to add its own charts. This implies **the creation of a chart tool** that users will use to choose how the report should be presented.
- **Reports export** outside DataPark should have more possibilities, now each chart can be exported as an image or the all report can be saved as PDF. Data should be available in CSV format for be used in other analysis outside the system if needed.
- **A more intuitive design of the page** that as the focus on facilitating the interaction with the platform by organizing the page content and the way they can be accessed.
- Add more data analysis with the **integration of new algorithms** already validated, for example, gait analysis.
- **Explore new opportunities of analysis**, like the freeze of gait or tremor episodes to include in the reports.
- Allow **automatic reports comparation** having a general overview of the different analysis performed and direct comparisons between reports.
- **Explore new devices** to gather data from patients, like smartphones or smartwatch. If needed to complement these new approaches build specific applications that allow getting a lot more information.

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Appendix A

Focus Groups

A.1 Preliminary Study

A.1.1 Protocol

Study Protocol

Designing data-driven reports for patients with Parkinson's and their clinicians

Tiago Guerreiro
11/12/2017

1

Context and Goals

Parkinson’s disease (PD) is one of the most common neurodegenerative disorders and the ageing of the population will largely increase the number of people living with PD, in the coming years. PD symptoms can go from tremor, extreme slowness and postural instability to impairment of cognitive function, speech, swallowing or sleep, among others. One of the characteristics of PD is that the disease progression is highly variable and the symptoms, alongside degree of disability, are likely to largely fluctuate over the duration of a day.

Challenges for clinical practice include understanding the progression of the disease, the response to pharmacological and nonpharmacological interventions, and the fluctuations the patient goes through alongside their possible explanations. However, the amount of information available for a clinician to understand these phenomena is scarce and highly subjective. First, assessments are made during clinical appointments which are spaced in time and are likely to miss fluctuations that happen throughout the day. Second, day to day events are normally assessed through patient paper diaries (e.g., to measure response outcomes to a new intervention) which are proven to have low compliance and are nothing but subjective.

The goal of this project is to develop and evaluate a novel holistic approach to medical consultations for Parkinson’s that is grounded on data, collected from heterogeneous sources, subjective and objective. With the goal of improving healthcare for people with Parkinson's, the project focuses on empowering clinicians with the ability to collect relevant day to day data from patients, parameterize interventions, and visualize an integrated whole of information, with the desirable granularity and continuous coverage over a monitoring period, that supports assessments and decision-making.

We propose to center the research project on a data-driven medical consultation platform, where clinicians can visualize integrated data from patients, and author personalized mobile and wearable interventions for each patient that may include:

1) Subjective outcomes collected with electronic diaries, variable in compliance-demand, from simple web interfaces to interactive voice response questionnaires, triggered by automatic scheduled calls;

2) Subjective outcomes collected (similarly as 1) from peers (e.g., family) that complement the information of the patient;

3) Objective outcomes collected from miniaturized activity sensors (e.g., activity bracelets) and mobile device sensors;

4) Objective outcomes collected from implicit (e.g., while typing text) and explicit interaction (e.g., playing an assessment game) with mobile devices or tablets.

The specific goal of this study is to understand and design, together with our stakeholders, the requirements and workflows of such platform. This includes understanding the type and detail of information desired by clinicians but also to understand what type of data patients would like to receive, and acceptance on how it will be collected.

The study will take place at CNS with their professionals and patients.

Participants

We will recruit two groups of participants:

- The first group will be composed of clinical professionals that work with patients with Parkinson. This includes neurologists, physiotherapists, and nurses;
- The second group will be composed of people with Parkinson that have previously participated in studies with technological solutions and have expectations regarding the future presentation of outcomes for their own understanding.

Procedure

This study will be composed of participatory design sessions with stakeholders. In these sessions, participants will be engaged with the researchers in defining the workflows, data, and their presentation, in the data-driven platform.

The study is split into two main parts: designing with clinicians and designing with patients.

3

Part 1: Designing with Clinicians

Overview of the Platform and Goals

The session will start with a presentation of the project and the session's goals:

> "Boa tarde, obrigado por participarem na sessão de hoje. O meu nome é Tiago Guerreiro e sou professor na Faculdade de Ciências e investigador no LASIGE. Estou acompanhado do Ricardo, César e Diogo, todos eles orientados por mim e a fazerem as suas teses na área da tecnologia de suporte à prática clínica, nomeadamente na avaliação e monitorização de pessoas com Parkinson. Nesse contexto, começámos a colaborar com o CNS (com o Joaquim Ferreira e com a Raquel Bouça) na avaliação funcional de pessoas com Parkinson usando sensores de movimento. Atualmente, estamos a desenhar uma plataforma que consiga oferecer aos clínicos uma visualização deste tipo de dados que seja relevante e usável, sem requerer conhecimentos técnicos, e possa ser introduzida na prática clínica. Paralelamente, queremos suportar, através da mesma plataforma, a realização de avaliações controladas (ex: testes de postura ou sit-to-stand-to-sit) de forma mais objectiva, e o agendamento de avaliações subjectivas, de forma a aumentar a qualidade da resposta.
>
> **Alguma questão/dúvida/comentário até agora?**
>
> Hoje vamos separar-nos em dois grupos de forma a agilizar a discussão. Em cada grupo, vamos pedir-vos para, de acordo com uma certa estrutura, opinarem e, em conjunto connosco, desenharem o que seria uma plataforma deste tipo, os dados mais interessantes a recolher, como os recolher, e como os apresentar. Três para um lado, três para outro, e nós também nos separamos."

Group 1: Sensor-based Clinic and Free Living Assessment

Free living assessment

[Ter preparado três folhas A3 com os títulos: **dispositivos, atividade / exercício, dados**. Criar mais folhas se virmos que aparece algum tema não previsto]

4

- “O nosso primeiro objetivo é potenciar uma avaliação menos fragmentada da evolução de um paciente e portanto permitir avaliar continuamente, de forma objetiva, a capacidade funcional do mesmo. Embora tenhamos falado em sensores de movimento, podemos pensar na monitorização de qualquer objeto ou no uso de dados de outros dispositivos já usados pelos pacientes. Portanto, de forma agnóstica ao dispositivo, que tipos de atividade, função, achariam interessante poder recolher e analisar para monitorização da doença de Parkinson?” **[Um investigador em cada grupo fica responsável por escrever e ir colocando os post-its nas folhas A3. Falar o suficiente mas deixar os clínicos falarem. Não tenham medo do silêncio; o silêncio obriga as pessoas a pensarem e a falar. Se estivermos sempre a falar, eles só confirmam os nossos comentários e para isso não precisávamos da sessão.]**
    - **Se (e só se) for preciso, dar exemplo da escova de dentes ou do telemóvel como dispositivos que poderíamos monitorizar.**
- Apresentar os sensores/ pulseiras e explicar que conseguimos recolher dados de atividade, identificar atividades (desde simples até atividades da vida diária), e detalhes bastante específicos da atividade (dar exemplo do GAIT, length, time, variability, asymmetry). “Agora de forma mais específica, imaginando o cenário em que a pessoa usa um sensor destes durante uma semana nas costas ou no pulso, que dados gostaria de poder ver, que sumários?” **[Continuar a colocar e deixar as pessoas colocarem post-its, se estiverem a ser muito rápidos]**
- (Se ainda não tiver sido abordado) “Agora, imaginem que a mesma pessoa muda a medicação e volta uma semana depois, e continua a usar o sensor. Quais os dados que poderiam ser importantes de contrastar?” **[Colocar post-its diferentes para mostrar quais devem ser apresentados em comparações]**
- Olhar para a folha dos “Dados” e, para cada tipo de dados, **deixar as pessoas desenharem o tipo de gráfico/tabela/número que gostam de ver para esses dados**. Colocá-los todos, organizados, numa folha A3. Se for necessário, dar exemplo do tipo de dados que temos e das transformações que podemos fazer. Questionar, se fizer sentido, variações por granularidade (ex: dia, semana). Discutir as várias sugestões e escolher representantes para cada tipo de dados. Marcar na folha A3 quais os seleccionados.
- Criar duas folhas A3: relatório para clínico e relatório para paciente. Começar pelo clínico e depois explicar que também é uma possibilidade entregar

relatórios a pacientes e pedir que nos ajudem nessa tarefa. **[Sem estragar as folhas anteriores, discutir e ir colocando nestas novas o que eles gostariam de ver. Se for preciso, criar post-its novos com outros dados.]**

Clinical assessment

[Ter preparado duas folhas A3 com os títulos: **exercício, dados**. Criar mais folhas se virmos que aparece algum tema não previsto]

- Repetir a apresentação do cenário, agora para os exercícios no laboratório.
- Questionar os exercícios que gostariam de medir e o que gostariam de medir.
- Pedir para desenharem os gráficos/tabelas/indicadores/etc.…que gostassem de ver. Discutir e escolher os melhores para cada tipo de dados.
- Compor o relatório do clínico e do paciente.

Group 2: Free Living Subjective Assessments

[Ter preparado quatro folhas A3 com os títulos: **dados/questionários, eventos, autoria, apresentação**. Criar mais folhas se virmos que aparece algum tema não previsto]

- Apresentar os problemas dos diários/questionários em casa. Falar de que forma estamos a tentar resolvê-los. Referir autoria por clínicos e resposta por meio digital ou IVR. Comentários e opiniões? **[Meter algo nos quadros se eles referirem]**
- Questionar o tipo de informação subjectiva que costumam ou gostariam de recolher de um paciente com Parkinson **[Preencher quadro de dados / questionários].**
- Questionar quando querem que essas questões sejam, respondidas. Qual o evento? **[Adicionar a quadro de eventos]**
- Apresentar as AxLE bands e falar do tipo de eventos que podemos detectar. Referir que estas bandas ou mesmo outros dispositivos podem ser triggers de questões. **[Perguntar por novos eventos (e dados a recolher)?]**
- Criar **cenários com o que recolhemos** para percebermos melhor o que eles conseguiriam fazer. Como gostavam de ver os dados apresentados? **[Usar os quadros de autoria e apresentação para representar o processo de autoria (cenário) e apresentação (gráfico/tabela/…) preferidos]**

6

- Então e se a aplicação para o paciente também servisse de “assistente” e, por exemplo, lhe indicasse para fazer um exercício em casa (recolhendo os dados com a pulseira). Quais os cenários interessantes? **Dados, autoria e apresentação disso?**
- Por último, há interesse em recolher dados de outras pessoas, por exemplo, cuidadores informais, família? Que tipo de dados? **Dados, autoria e apresentação disso?**

Consolidation

Se possível, cada grupo apresenta o resultado ao outro grupo, oralmente e eventualmente com suporte aos quadros finais. Discute-se um pouco. Faremos um relatório, que pode depois ser comentado por todos.

7

Part 2: Designing with Patients

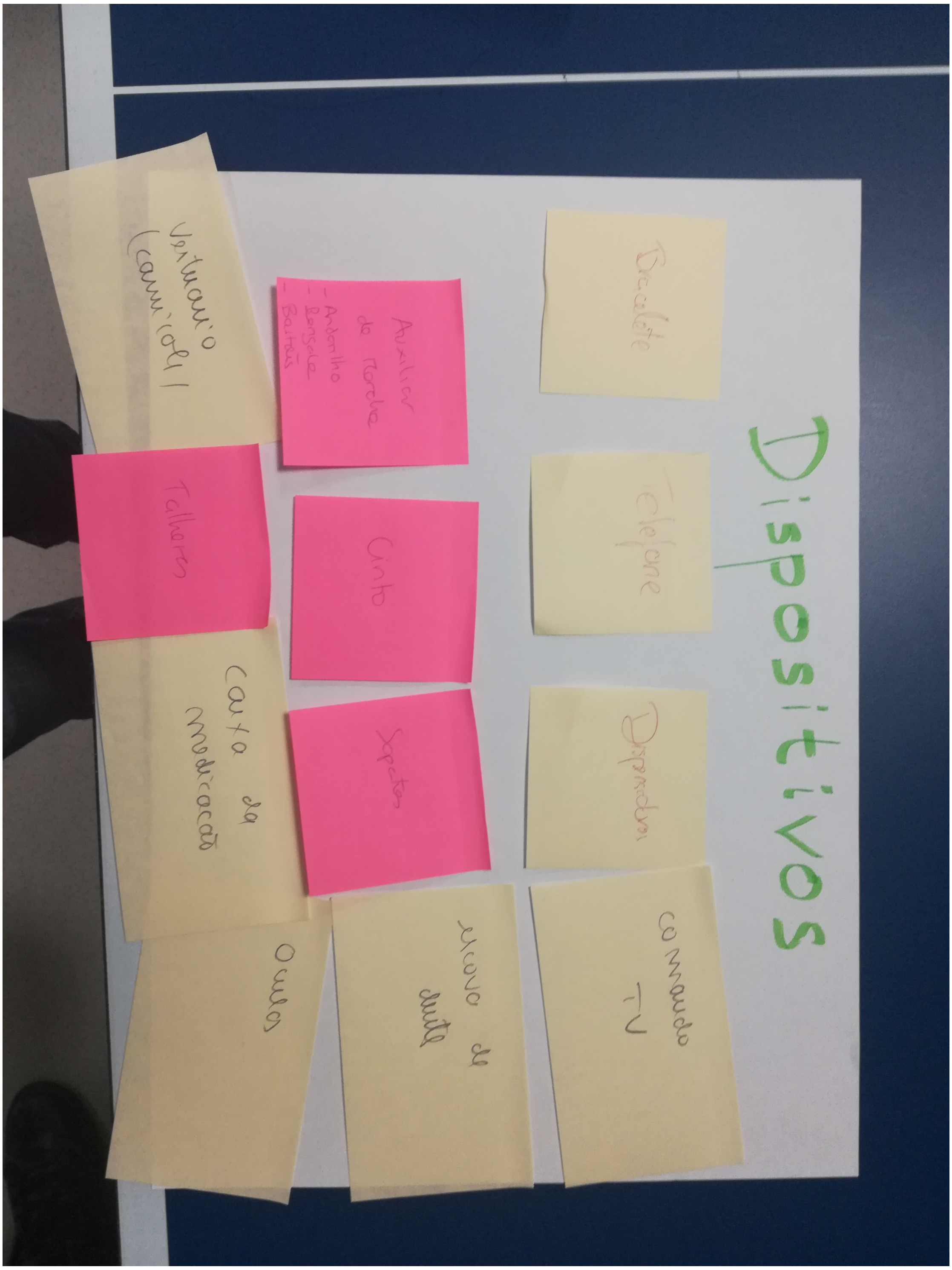
Overview of the Platform and Goals

Objectives

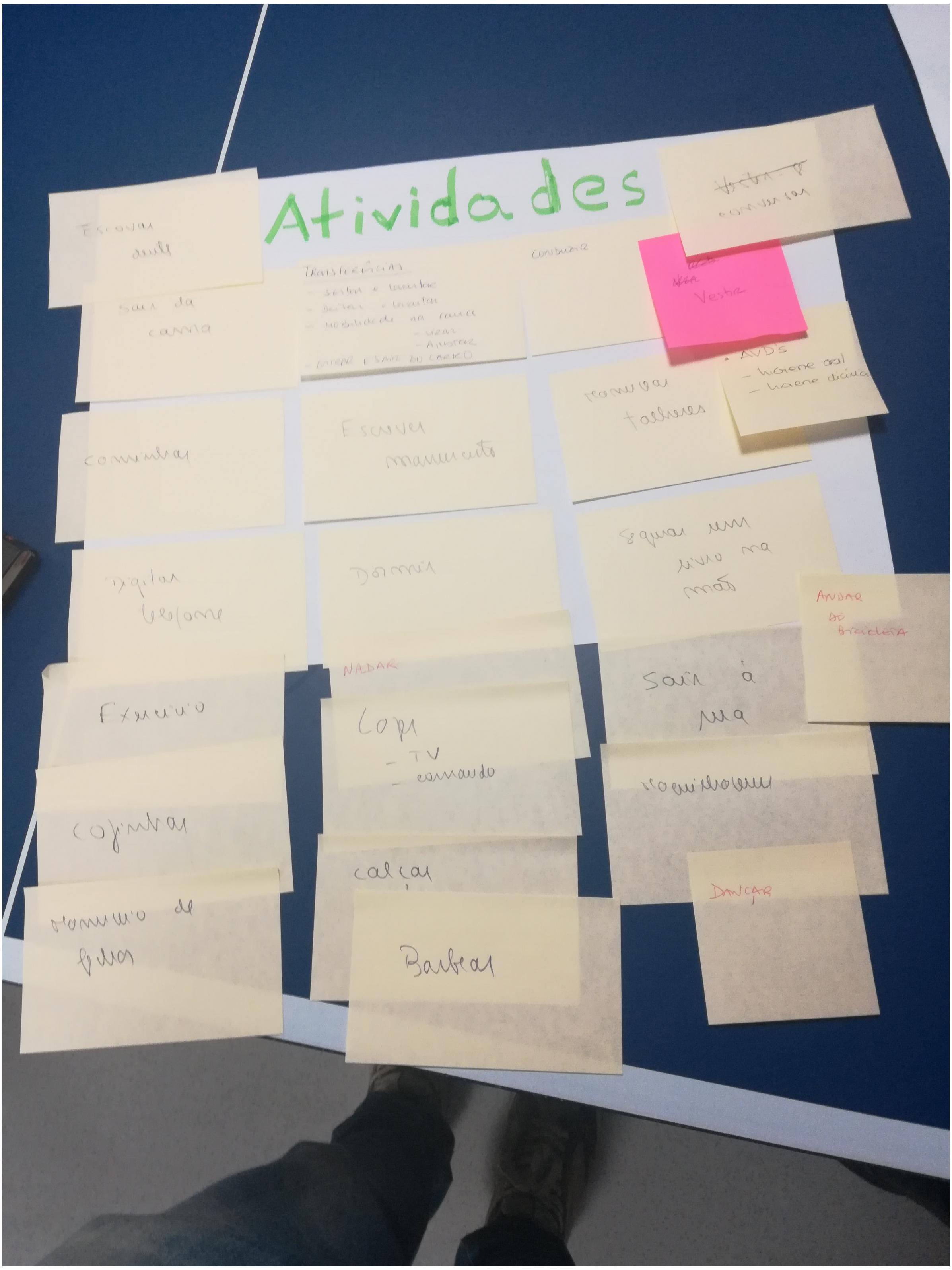
- Explicar qual o uso que irá ser dado aos sensores e de que forma irá contribuir para os pacientes. Perguntar o nível de aceitação do uso do mesmo, bem como perceber se existe algum desconforto e, em caso afirmativo, como podemos melhorá-lo.
- Descrever o objetivo dos lembretes (Digital/IVR), explicar de forma simples para que possam perceber de que forma lhes irá ser útil. Novamente perceber o nível de aceitação nas utilização das ferramentas
- Questionar sobre como gostariam de ser alertados de forma a se sentirem mais auxiliados durante o dia-a-dia, sobretudo quando não se encontram na presença de peers(família, amigos ou cuidadores).
- Perceber o que os pacientes acham relevantes dar como informação para o médico (sobretudo perceber a perspectiva do paciente sobre o que deve ser considerado importante ou útil para uma análise).
- Falar sobre a importância dos peers (familia, amigos e cuidadores) e questionar sobre qual a informação que seria possivel retirar a partir destes e que pode complementar a informação obtida direta/indiretamente quer pelo médico quer pelo paciente.
- Finalmente, perceber o que seria relevantes para os pacientes obter como informação que lhes pudesse ser útil para tentarem perceber de melhor forma como se sentem. **[Não só a nível de relatório físicos mas também referir se notificações ou chamadas sobre o estado podiam ser úteis ou demasiado intrusivas]**

A.1.2 Paper Boards

Devices Board

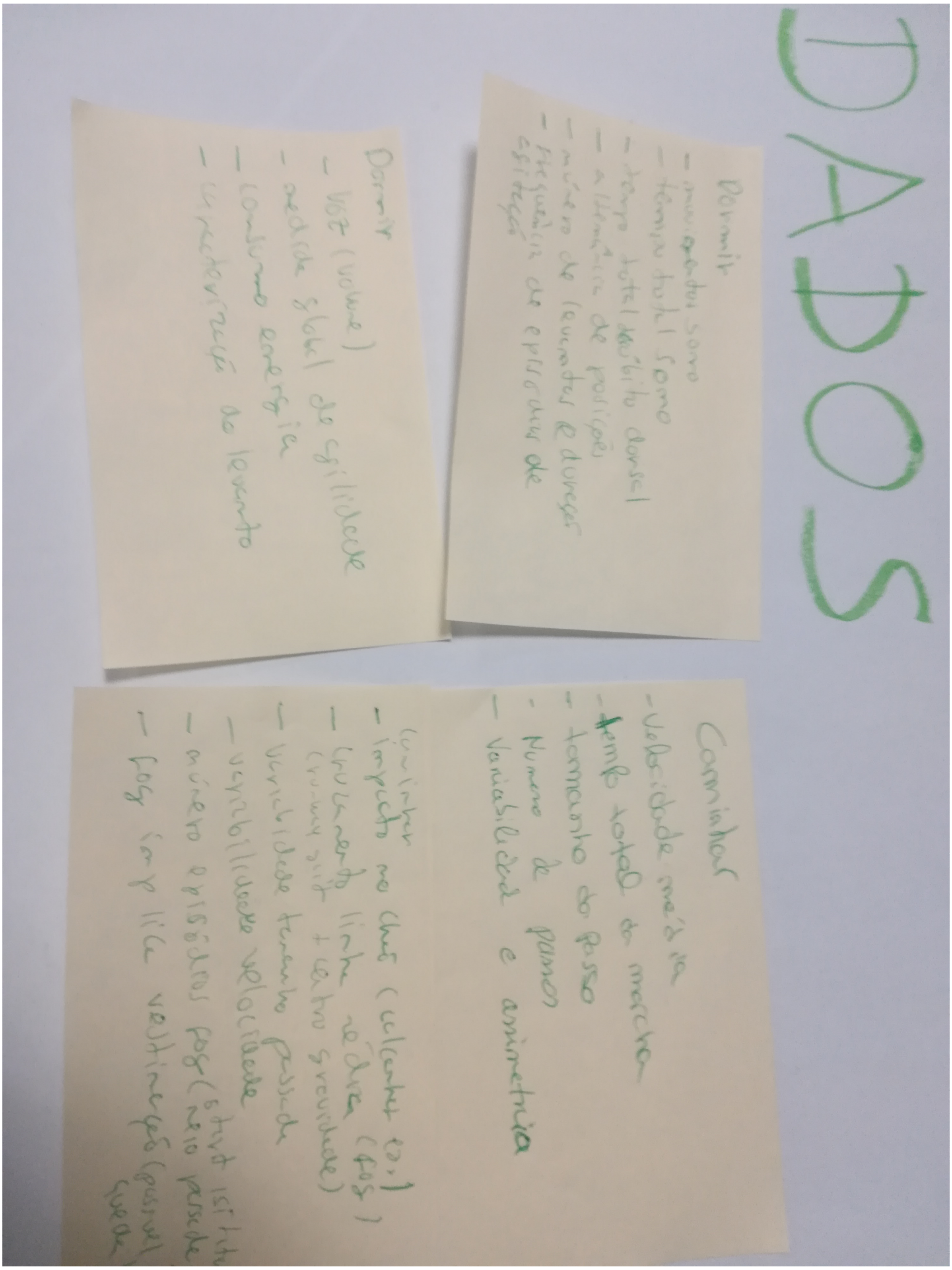


Activities Board



Data Board

Grouped by different activities previous selected from the ones more relevant for participants



A.1.3 Reports

Report 1

- Tempo diário de caminhada
- Tempo de sono (Intensidade)
- Nº de vezes WC (frequência, duração)
- Nº Quedas / Nº quase Quedas
- Variação Frequência Cardíaca - o que motiva / em que momento
- Hora da toma da medicação
- Duração das refeições
- Hora de acordar
- Realização Higiene / Higiene Oral
- Velocidade da marcha
- Momentos do dia com alteração da voz
- Frequência e tempo de convivência social
- Alternância de decúbitos durante o sono
- Monitorizar saída da cama
- Transição posição (Sentar/levantar)
    - tempo que demora
    - Frequência
- Movimentos involuntários noturnos
- Episódios de incontinência (Humidade)
- Nº momentos recreativos (leitura, TV)
-

Report 2

- sono (qualidade/duração)
- cuidados de higiene oral / corporal
- Adesão à medicação
- Marcha (principais problemas)
- Frequência ou duração de atividades sociais e recreativas
- Principais dificuldades sentidas no dia / horário em que acontecem (manuseamento talheres, calçar, vestir/despir, ...)
- Tempo de inactividade (diurno)
-

Report 3 Part 1

Relatório

- 7 dias
- Total distância percorrida
- Tempo marcha
- Tempo em pé
- Tempo sentado
- Tempo deitado
- Tempo dormir
- velocidade da marcha
- Total tempos bons (boa funcionalidade)
- Total tempos maus (má funcionalidade)
- N: quedas
- N: de quase queda
- Nº bloqueios da marcha
- N: levante durante a noite
- Tempo para mudar de posição de sentado para de pé de manhã para se levantar da cama
- Tempo de movimentos involuntários excessivos
- Tempo de grande imobilidade durante o dia (estando vígil)

Report 3 Part 2

Hora de levantar da cama

Hora de deitar

Tempo de transição de sentado para de pé nas várias tentativas do dia

Duração do tempo das refeições

Consumo total de energia diário

Nº de transições de OFF para ON em termos de transição de imobilidade para > agilidade

Nº de rotações na cama durante a noite

Report 4

• CARACTERIZAÇÃO DA MARCHA

TESTES DA MARCHA — comprimento do passo

TUG — nº de passos

TESTE 10 METROS MARCHA — c/ dupla tarefa

— s/ dupla tarefa

— Base sustentação, C.G, cruzamento linha média.

— velocidade

• Equilíbrio — limites de estabilidade (em pé e sentado)

. Parametros da estab. — Transferências de peso

Mini-Best TEST. —

• FORÇA Sit to stand — Qtas vezes e Qto tempo e Qtas tentativas.

• Resistência cardiovascular (capacidade física)

— FADIGA

— Fcardiaca.

— StO_2%.

• Actividades de vida diária — VESTIR (DESPIR/calças)

— Higiene

— Alimentação.

— Actividade profissional.

— Actividade social

• Nível de actividade física

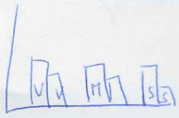
• Transferências

• Episódios de Quedas e Quais e Quantas.

Report 5 Part 1

- ~~Atividade~~:

~~2º dia vs 6º dia: tempo total~~ tempo total ⊕ 2º vs 6º dia:

↳ sedentário, moderada, vigorosa  TOTAL  2º vs 6º

↳ Tempo ⊕ bloqueado antes e depois da toma da medicação (wearing-off)

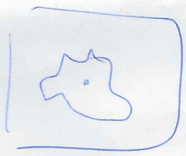
↳ movimentos involuntários em relação às tomas da medicação

↳ Fadiga associada à atividade moderada / vigorosa

- Marcha:

↳ comparando c/ valores de referência

- Tamanho do passo
- Velocidade de marcha
- Bloqueios de marcha
- Assimetria
- Variabilidade
- Festinação (passos pequenos)

- Equilíbrio →  parado e durante a marcha para que lado balança mais

- Transferências:

↳ ~~Ato~~ movimentos durante a noite

↳ tempo que demora a tarefa: sentar/levantar

↳ se é feito de forma ⊕/⊖ brusca: sentar/levantar

- Tremor:

↳ Altura do dia c/ mais tremor

↳ Amplitude do tremor.

- Voz:

↳ volume

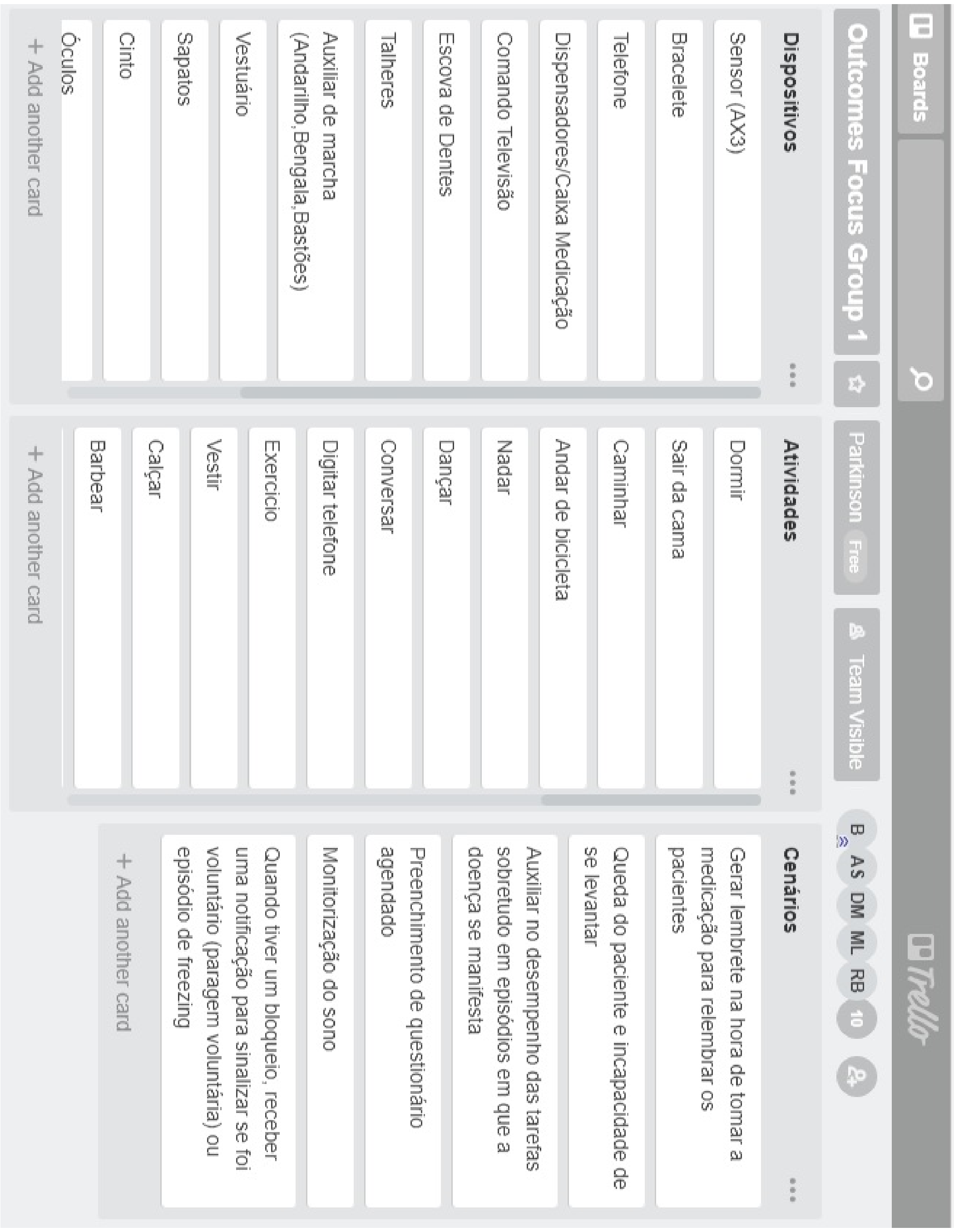
↳ Perceptível - articulação das palavras

Report 5 Part 2

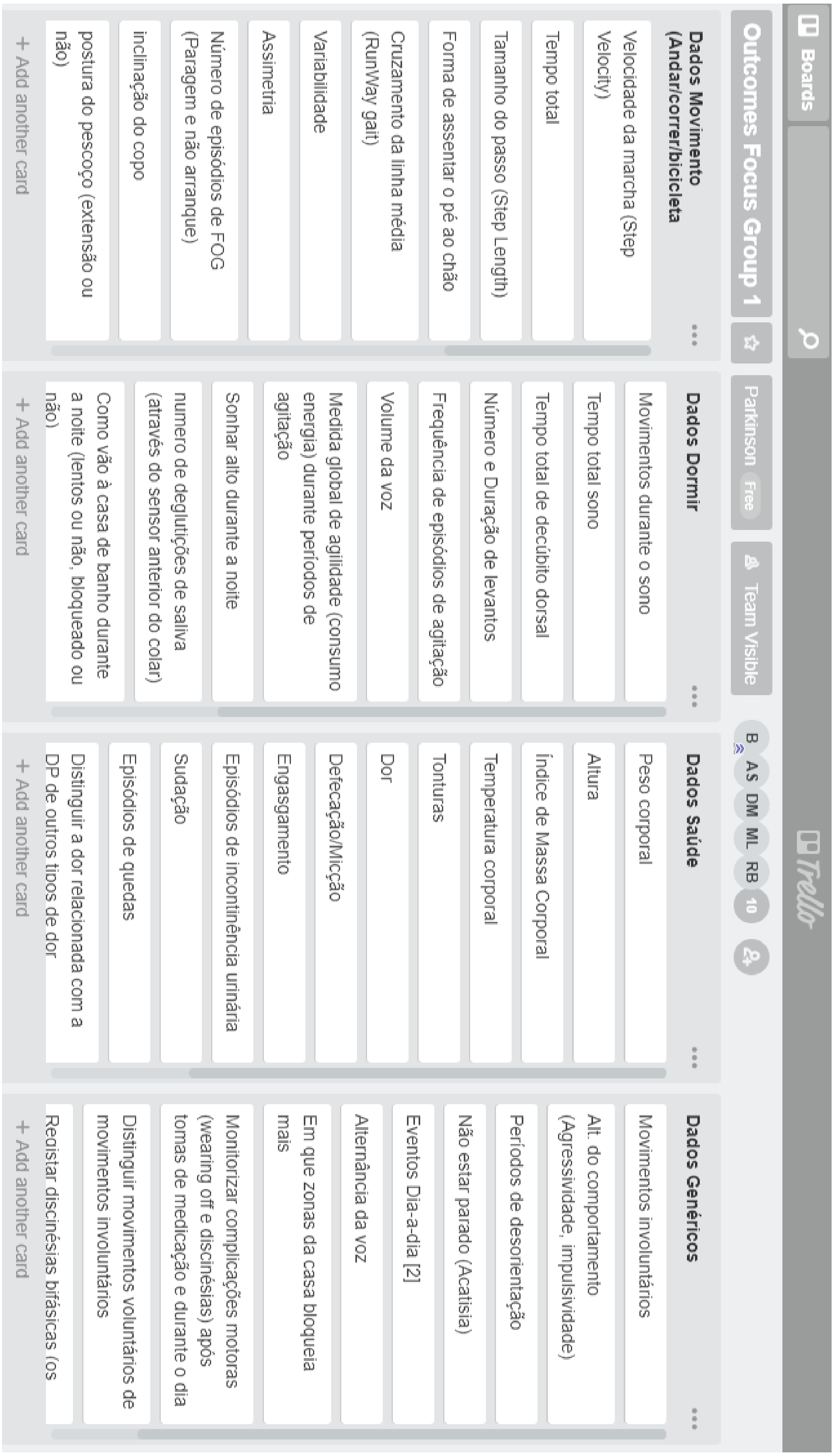
- Quedas:
  - Nº
  - Direção – Frente, trás, lados
- Sudação
- Alterações da Pressão arterial com mudança de posição.
- ~~Engasgamen~~
- Alteração do peso
- Engasgamento
- ↑ saliva na boca.
- Tempo sem o sensor.

A.1.4 Digital Boards

Devices, Activities and Scenarios Boards



Data Boards


Boards
Outcomes Focus Group 1
Parkinson Free
Team Visible
B AS DM ML RB 10
Trello
Dados Movimento (Andar/correr/bicicleta
Velocidade da marcha (Step Velocity)
Tempo total
Tamanho do passo (Step Length)
Forma de assentar o pé ao chão
Cruzamento da linha média (RunWay gait)
Variabilidade
Assimetria
Número de episódios de FOG (Paragem e não arranque)
inclinação do copo
postura do pescoço (extensão ou não)
+ Add another card
Dados Dormir
Movimentos durante o sono
Tempo total sono
Tempo total de decúbito dorsal
Número e Duração de levantos
Frequência de episódios de agitação
Volume da voz
Medida global de agilidade (consumo energia) durante períodos de agitação
Sonhar alto durante a noite
numero de deglutições de saliva (através do sensor anterior do colar)
Como vão à casa de banho durante a noite (lentos ou não, bloqueado ou não)
+ Add another card
Dados Saúde
Peso corporal
Altura
Índice de Massa Corporal
Temperatura corporal
Tonturas
Dor
Defecação/Micção
Engasgamento
Episódios de incontinência urinária
Sudação
Episódios de quedas
Distinguir a dor relacionada com a DP de outros tipos de dor
+ Add another card
Dados Genéricos
Movimentos involuntários
Alt. do comportamento (Agressividade, impulsividade)
Periodos de desorientação
Não estar parado (Acatisia)
Eventos Dia-a-dia [2]
Alternância da voz
Em que zonas da casa bloqueia mais
Monitorizar complicações motoras (wearing off e discinésias) após tomas de medicação e durante o dia
Distinguir movimentos voluntários de movimentos involuntários
Registar discinésias bifásicas (os
+ Add another card

Appendix B

Longitudinal Study Online Survey

Questionário aos clínicos do estudo longitudinal do DataPark

Este questionário é elaborado no âmbito de uma tese de mestrado da Faculdade de Ciências da Universidade de Lisboa. Tem como objectivo recolher a sua opinião sobre a utilização da plataforma DataPark.
O DataPark é composto por duas vertentes: avaliação clínica e avaliação funcional. A plataforma divide-se numa aplicação móvel, para apoio às avaliações clinicas, e uma aplicação web, para visualização dos dados e geração de relatórios.
Este estudo decorre de uma colaboração com o CNS (Campus Neurológico Sénior) e tem como principal foco uma avaliação preliminar do uso do DataPark no apoio dos clínicos no decorrer das suas funções e lhes permitir ter acesso a mais dados sobre os seus pacientes quer em avaliação clínica quer em avaliação funcional

O questionário será breve, agradecemos uma resposta criteriosa a todas as questões propostas.

Obrigado.

*Required

1. **Email address** *

Informações Pessoais

Informação biográfica sobre o clínico.

2. **Nome:** *

3. **Idade:** *

Mark only one oval.

- Menos de 30
- 30-40
- 41-50
- 51-60
- 61-70
- Mais de 70

4. **Sexo:** *

Mark only one oval.

- Masculino
- Feminino

5. **Profissão** *

Mark only one oval.

- Fisioterapeuta
- Enfermeiro
- Other:

Pacientes

Informação de contexto sobre os pacientes que tiveram contacto com o clínico.

6. **Quantos pacientes foram avaliados por si em contexto de avaliação clínica com sensores?** *

7. **Quantos pacientes foram avaliados por si em contexto de avaliação funcional com sensores?** *

8. **Existiram alterações na forma como lida com o paciente pelo uso de sensores ?** *

9. **Existiram alterações no paciente pelo uso sensores?** *

Caracterização da Aplicação móvel

Aplicação usada nas avaliações clínicas aos pacientes.

10. **Teve algum contacto com o DataPark versão aplicação móvel?** *

Mark only one oval.

- Sim *Skip to question 10.*
- Não *Skip to question 17.*

Caracterização da Aplicação móvel

Aplicação usada nas avaliações clínicas aos pacientes.

11. **O uso da aplicação influenciou o tempo de execução das tarefas?** *

Mark only one oval.

	1	2	3	4	5	
Pouco						Muito

12. **Durante a avaliação de que forma a aplicação influenciou o cuidado a ter com os pacientes** *
Mark only one oval.

	1	2	3	4	5	
Pouco	⬭	⬭	⬭	⬭	⬭	Muito

13. **Como classifica o tempo de aprendizagem para a aplicação?** *
Mark only one oval.

	1	2	3	4	5	
Pouco	⬭	⬭	⬭	⬭	⬭	Muito

14. **Qual o grau de dificuldade sentido ao lidar com aplicação?** *
Mark only one oval.

	1	2	3	4	5	
Reduzido	⬭	⬭	⬭	⬭	⬭	Elevado

15. **Quais os maiores problemas/dificuldades que sentiu ao usar a aplicação móvel?** *

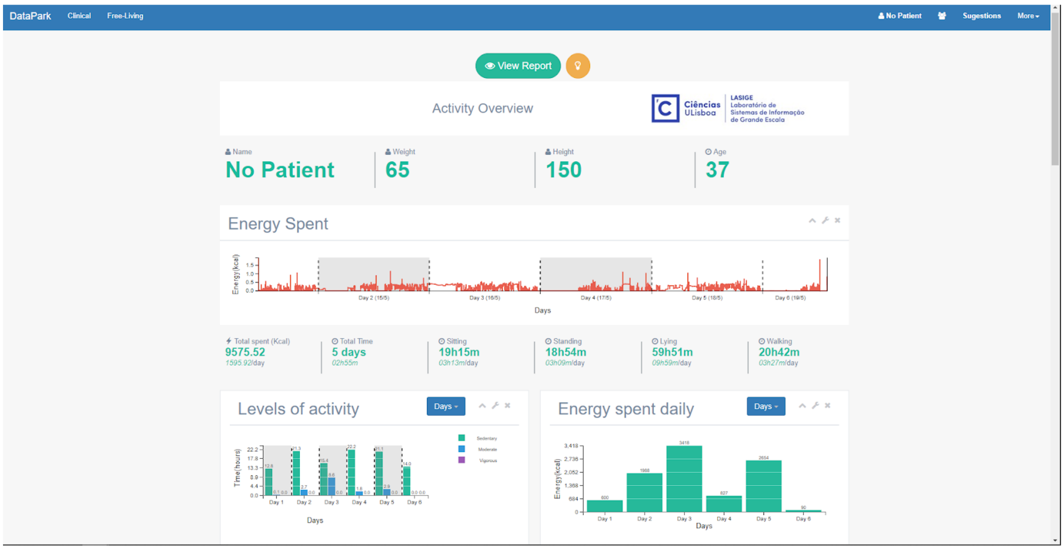
16. **Como classifica o impacto que a aplicação tem durante a realização das avaliações clínicas?** *
Mark only one oval.

	1	2	3	4	5	
Reduzido	⬭	⬭	⬭	⬭	⬭	Elevado

17. **Se desejar acrescentar mais alguma informação sobre o tema por favor indique-nos aqui**

Caracterização da Aplicação web

Aplicação usada para visualização dos dados e geração de relatórios.



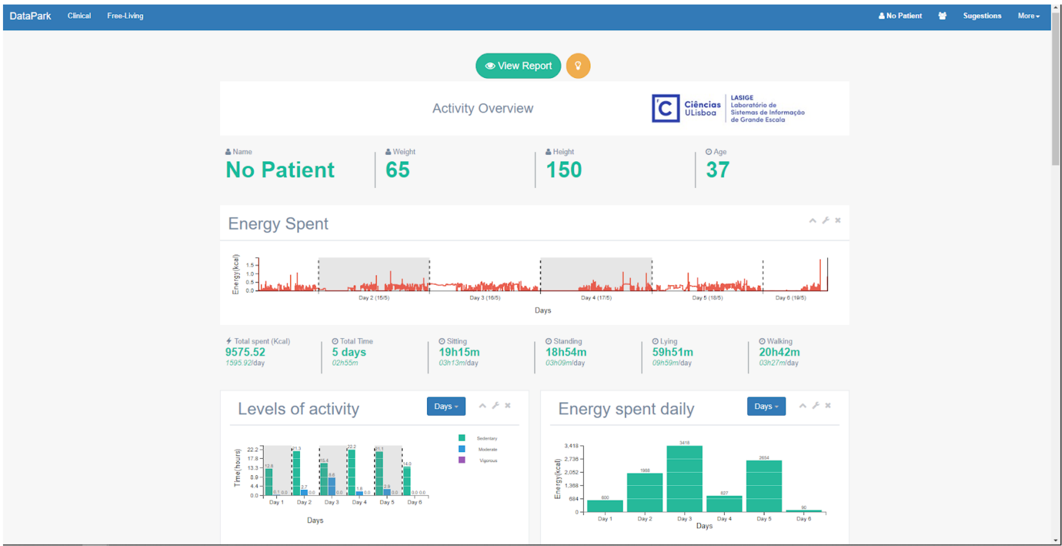
18. **Teve algum contacto com o DataPark versão aplicação web?** *

Mark only one oval.

- ⬭ Não *Skip to question 24.*
- ⬭ Sim *Skip to question 18.*

Caracterização da Aplicação web

Aplicação usada para visualização dos dados e geração de relatórios.



19. **O uso da aplicação web influenciou o tempo de execução das tarefas?** *

Mark only one oval.

	1	2	3	4	5	
Pouco	⬭	⬭	⬭	⬭	⬭	Muito

20. **Como classifica o tempo de aprendizagem para a aplicação web?** *

Mark only one oval.

	1	2	3	4	5	
Pouco						Muito

21. **Qual o grau de dificuldade sentido ao lidar com aplicação web?** *

Mark only one oval.

	1	2	3	4	5	
Reduzido						Elevado

22. **Quais os maiores problemas/dificuldades que sentiu ao usar a aplicação web?** *

23. **Como classifica o impacto que a aplicação web teve para a posterior análise dos dados do paciente?** *

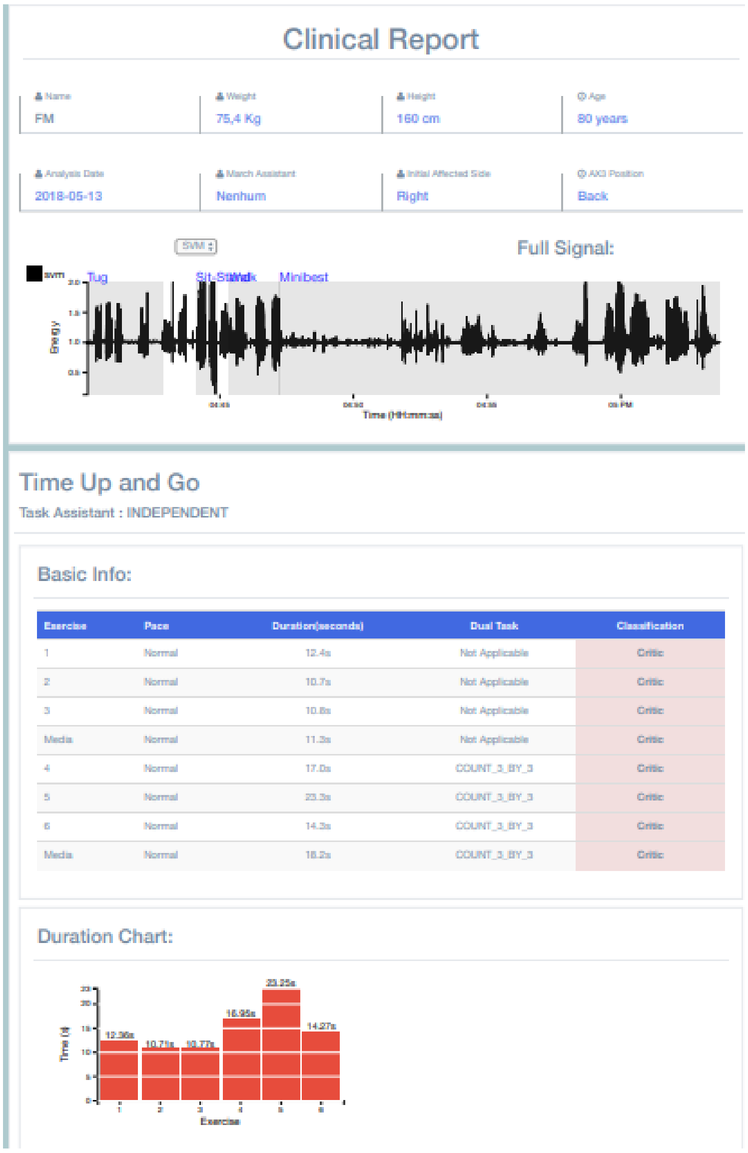
Mark only one oval.

	1	2	3	4	5	
Reduzido						Elevado

24. **Se desejar acrescentar mais alguma informação sobre o tema por favor indique-nos aqui**

Caracterização dos relatórios de avaliação clínica

Informação sobre os relatórios de avaliação clínica.



Clinical Report

Name	Weight	Height	Age
FM	75,4 Kg	160 cm	80 years

Analysis Date	March Assistant	Initial Affected Side	AX3 Position
2018-05-13	Nenhum	Right	Back

Time Up and Go

Task Assistant : INDEPENDENT

Basic Info:

Exercise	Pace	Duration(seconds)	Dual Task	Classification
1	Normal	12.4s	Not Applicable	Critic
2	Normal	10.7s	Not Applicable	Critic
3	Normal	10.8s	Not Applicable	Critic
Media	Normal	11.3s	Not Applicable	Critic
4	Normal	17.0s	COUNT_3_BY_3	Critic
5	Normal	23.3s	COUNT_3_BY_3	Critic
6	Normal	14.3s	COUNT_3_BY_3	Critic
Media	Normal	18.2s	COUNT_3_BY_3	Critic

Duration Chart:

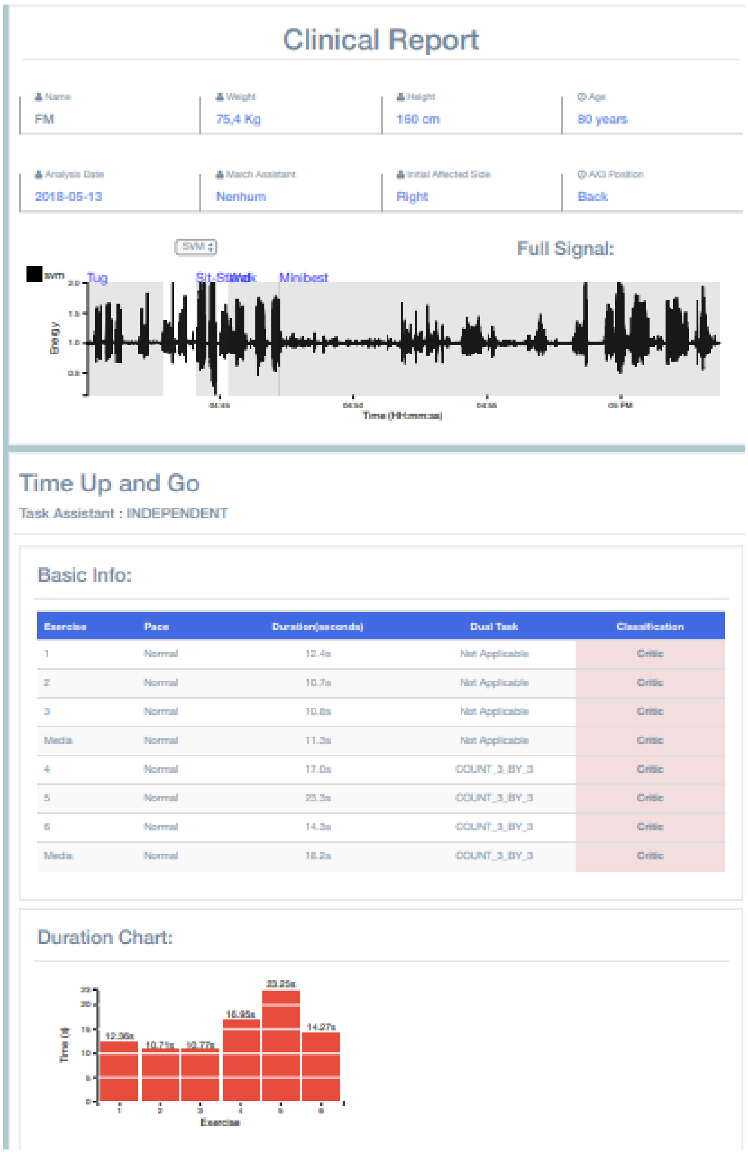
25. **Teve algum contacto com os relatórios produzidos pelo Datapark em avaliação clínica?** *

Mark only one oval.

- ◯ Sim *Skip to question 25.*
- ◯ Não *Skip to question 31.*

Caracterização dos relatórios de avaliação clínica

Informação sobre os relatórios de avaliação clínica.



Clinical Report

Name: FM
Weight: 75,4 Kg
Height: 160 cm
Age: 80 years

Analysis Date: 2018-05-13
March Assistant: Nenhum
Initial Affected Side: Right
AX3 Position: Back

SVM

Full Signal:

svm
Tug
Sit-Stand
Walk
Minibest
Energy
Time (HH:mm:ss)

Time Up and Go

Task Assistant : INDEPENDENT

Basic Info:

Exercise	Pace	Duration(seconds)	Dual Task	Classification
1	Normal	12.4s	Not Applicable	Critic
2	Normal	10.7s	Not Applicable	Critic
3	Normal	10.8s	Not Applicable	Critic
Media	Normal	11.3s	Not Applicable	Critic
4	Normal	17.0s	COUNT_3_BY_3	Critic
5	Normal	23.3s	COUNT_3_BY_3	Critic
6	Normal	14.3s	COUNT_3_BY_3	Critic
Media	Normal	18.2s	COUNT_3_BY_3	Critic

Duration Chart:

26. **A nível de compreensão dos relatórios considera-os de:** *
Mark only one oval.

	1	2	3	4	5	
Fácil	⬭	⬭	⬭	⬭	⬭	Difícil

27. **Os relatórios foram discutidos com os pacientes?** *
Mark only one oval.

⬭ Sim
⬭ Não

28. **Qual foi a reacção e comentários dos pacientes aos relatórios?** *

29. **Considera que os dados recolhidos em avaliação clínica contribuem para um melhor conhecimento sobre o paciente?** *
Mark only one oval.

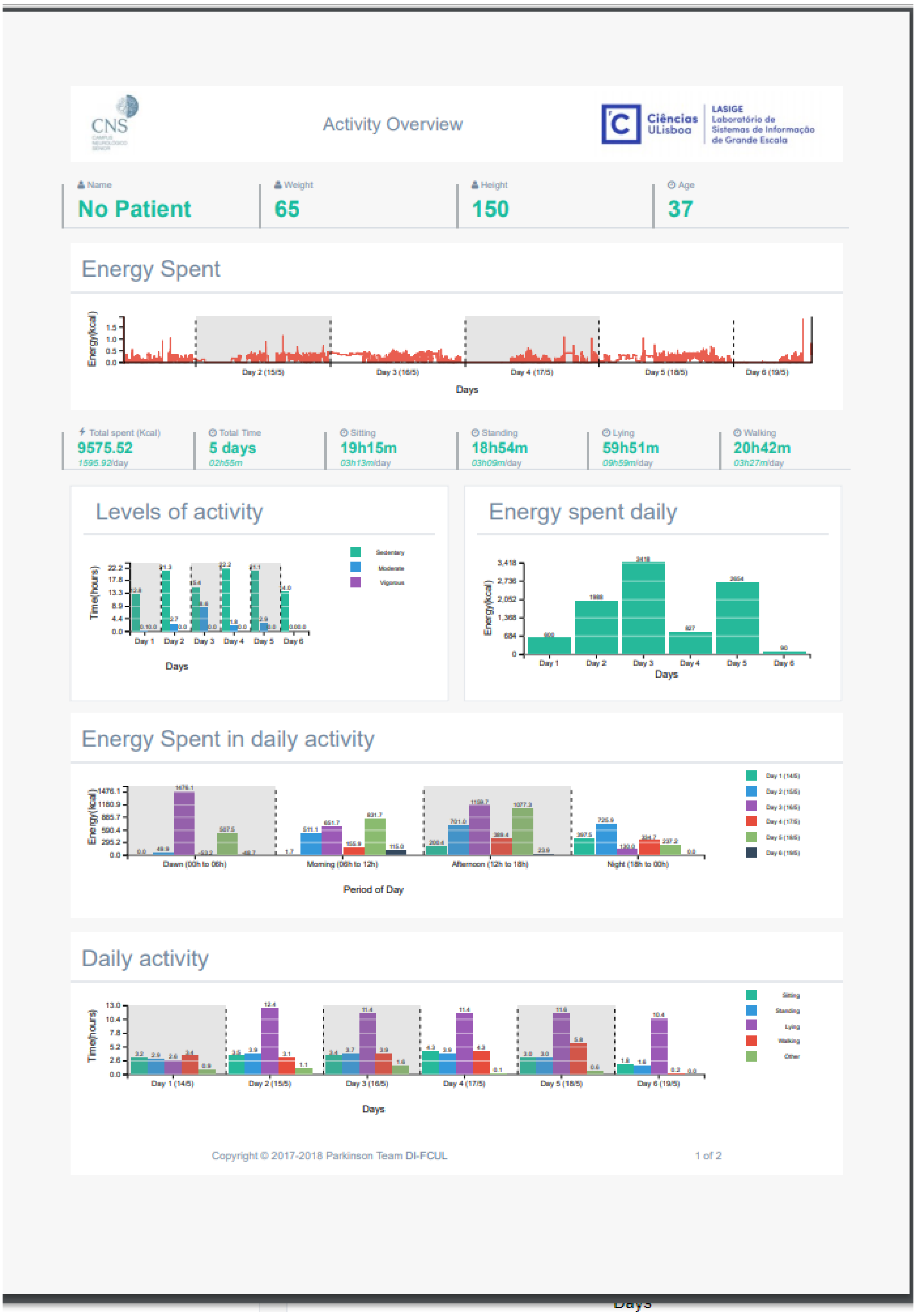
- Sim
- Não

30. **Que tipo de informação achou mais útil nos relatórios?** *

31. **Se desejar acrescentar mais alguma informação sobre o tema por favor indique-nos aqui**

Caracterização dos relatórios de avaliação funcional

Informação sobre os relatórios de avaliação funcional.



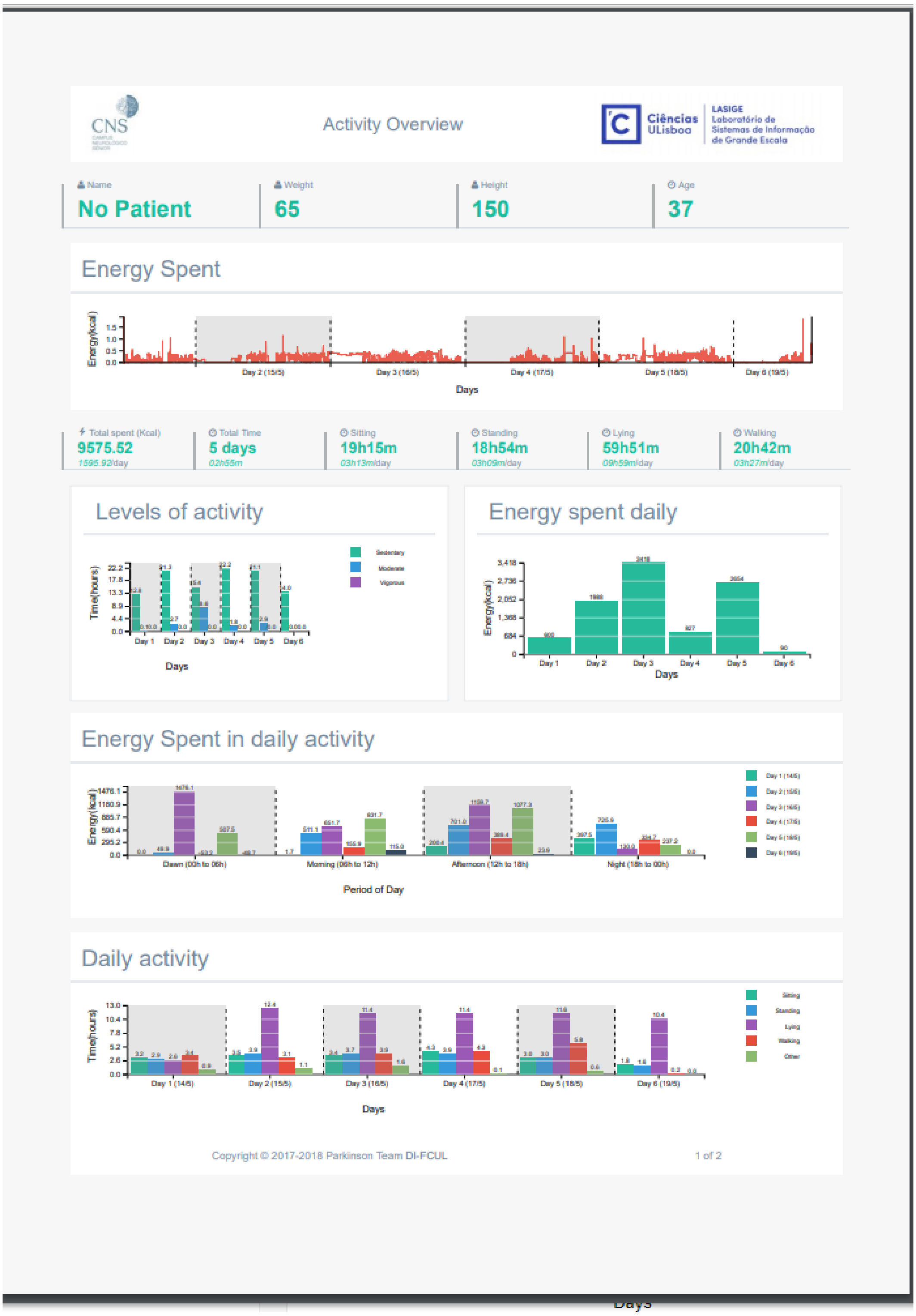
32. **Teve algum contacto com os relatórios produzidos pelo Datapark em avaliação funcional?** *

Mark only one oval.

- Sim *Skip to question 32.*
- Não *Skip to question 38.*

Caracterização dos relatórios de avaliação funcional

Informação sobre os relatórios de avaliação funcional.



33. **A nível de compreensão dos relatórios considera-os de:** *
Mark only one oval.

	1	2	3	4	5	
Fácil	◯	◯	◯	◯	◯	Díficil

34. **Os relatórios foram discutidos com os pacientes?** *
Mark only one oval.

- Sim
- Não

35. **Qual foi a reacção e comentários dos pacientes aos relatórios?** *

36. **Considera que os dados recolhidos em avaliação funcional contribuem para um melhor conhecimento sobre o estado do paciente fora do ambiente clínico?** *
Mark only one oval.

- Sim
- Não

37. **Que tipo de informação achou mais útil nos relatórios?** *

38. **Se desejar acrescentar mais alguma informação sobre o tema por favor indique-nos aqui**

Funcionalidades DataPark

Informação sobre as diferentes funcionalidades do DataPark e que impacto tiveram para os clínicos

39. **Na sua opinião quais os aspectos negativos que os dados obtidos pelo sensor trazem na avaliação do paciente?** *

40. **Na sua opinião quais os aspectos positivos que os dados obtidos pelo sensor trazem na avaliação do paciente?** *

41. **Classifique as funcionalidades do DataPark de acordo com as que considera mais e menos importantes** *
Escolha NA quando não tiver opinião formada sobre alguma das funcionalidades
Mark only one oval per row.

	NA	Pouco Útil	Útil	Muito Útil
Aplicação móvel				
Exportar relatório para PDF				
Exportar gráficos como imagem				
Visualização na plataforma do relatório				
Adicionar filtros aos dados				
Construir o próprio relatório				
Processo de Registo dos Utilizadores				
Caixa de Sugestões				

42. **Se desejar acrescentar mais alguma informação sobre o tema por favor indique-nos aqui**

☐ Send me a copy of my responses.